CHILD DEATH & SERIOUS INJURY
REVIEW COMMITTEE

Annual Report 2020–2021

Government
of South Australia

GPO Box 1152
ADELAIDE SA 5001

T 08 8463 6451
F 08 8463 6444

E cdsirc@sa.gov.au
W www.cdsirc.sa.gov.au

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Letter of Transmission

Hon John Gardner MP
Minister for Education

Dear Minister

I submit to you for presentation to Parliament, the 2020–21 Annual Report of the South Australian Child Death and Serious Injury Review Committee which has been prepared pursuant to Part 4 of the *Children and Young People (Oversight and Advocacy Bodies) Act 2016*.

This report highlights the Committee's activities in fulfilling its statutory obligations.

In compliance with the *Public Sector Act 2009* and the *Public Finance and Audit Act 1987*, a further report concerning the management of human resources and financial issues of the Committee has been submitted as part of the Annual Report of the Department for Education for 2020–21.

Submitted on behalf of the Child Death and Serious Injury Review Committee by:

Dr Mark Fuller
Acting Chair
Child Death and Serious Injury Review Committee
22 October 2021

Committee's Foreword

The Child Death and Serious Injury Review Committee is pleased to present its sixteenth annual report to Parliament. This report is provided under Part 4 of the *Children and Young People (Oversight and Advocacy Bodies) Act 2016*.

In July 2021, the Committee farewelled its Chair, Ms Meredith Dickson QC. The Committee thanks Meredith for her leadership and commitment to strengthening the Committee's strategic alliances and expanding the ways in which it contributed to the prevention of child deaths.

In June, the Committee also farewelled two of its long-standing members – Dr Deepa Jeyaseelan and Ms Di Gursansky. These members share a deep commitment to improving the lives of South Australia's children. Their dedication to the care of children and their expertise will be missed.

This year's annual report demonstrates the broad scope of the Committee's work. The Committee has considered the deaths of infants from the perspective of the history of their parents and made recommendations about the services that are needed to support young people whose lives have been impacted by trauma. Using its data about the circumstances of sudden unexpected deaths of infants, the Committee worked with Kidsafe SA, one of its key prevention partners, to host a forum about this matter. Also in conjunction with Kidsafe SA, the Committee has brought to the attention of South Australian policy-makers the need to consider the safety of children in road safety strategies.

One of the Committee's great strengths is its multi-disciplinary membership. When reviewing the circumstances and cause of each death, members bring their particular knowledge and expertise about the issues confronting families, children and young people, or the challenges faced by services to provide for the needs of every child. The combination of these contributions provides a sound basis for decision-making about systemic issues in the circumstances of a death that, if changed, might prevent the deaths of other children in similar circumstances.

While its work is at times confronting, the Committee believes that much can, and should, be learned from its reviews of child deaths. A major challenge the Committee continues to face is gaining the attention of legislators, policy-makers, and practitioners whose role it is to make a positive difference to the lives of children and young people.

The Committee thanks those agencies that have been willing to demonstrate the capacity to recognise and accept the need for change and embrace the benefit of listening to an independent source of evidence.

Children die from many different causes. Each death is a tragedy, and the Committee extends its sympathy to the families, friends, communities, and professionals who have loved and cared for those children who have died. The Committee hopes that this report assists the efforts of those who work to keep children safe.

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Glossary

ABS	Australian Bureau of Statistics
Act	*Children and Young People (Oversight and Advocacy Bodies) Act 2016*
ANZCDR & PG	Australian and New Zealand Child Death Review and Prevention Group
Average	Arithmetic mean
CDSIRC	Child Death and Serious Injury Review Committee
Child	In this report 'child' includes infants, children and young people from birth up to and including 17 years
DE	Department for Education
DCP	Department for Child Protection
DHS	Department of Human Services
ICD-10	International Classification of Disease (Version 10)
Infant	A child under one year of age
Neonate	An infant up to and including 28 days of age
POU	Pregnancy Outcome Unit, Wellbeing SA, SA Health
SEIFA	Socio-Economic Indexes for Areas, Index of Relative Socio-economic Disadvantage (IRSD)
SIDS	Sudden Infant Death Syndrome
SUDI	Sudden Unexpected Death in Infancy

Acknowledgements

- Australian and New Zealand Child Death Review and Prevention Group (ANZCDR & PG)
- Office of Births, Deaths and Marriages
- Department of Human Services which continues to provide technical advice and support for the Committee's database, and assistance with records management
- Department for Education for support with administrative, financial and human resource management
- Kidsafe SA
- National Centre for Health Information Research and Training, Queensland University of Technology, especially Ms Sue Walker, Director
- Pregnancy Outcome Unit, Wellbeing SA, SA Health
- SA Health, Local Health Networks' staff and the staff of SA Pathology for their prompt responses to the Committee's requests for information
- SA Police for their diligent attention to collecting information about child deaths
- State Coroner and staff
- Chief Executives and senior officers from the Department for Child Protection, the Department for Education, the Department of Human Services, SA Health and SA Police for contributing to the Committee's understanding of service delivery within their departments.

Committee Members

Chair

Ms Meredith Dickson QC	until 26 July 2021

Members

Dr Mike Ahern	
Ms Angela Davis	
Dr David Everett OAM	
Dr Mark Fuller	
Ms Dianne Gursansky	until 24 June 2021
Ms Ann-Marie Hayes	
Dr Deepa Jeyaseelan	until 24 June 2021
Ms Karen McAuley	from 17 August 2020
Dr Margaret Kyrkou OAM	
Mr Kurt Towers	
Dr Mohammed Usman	from 17 August 2020
Ms Kylie Walsh	from 17 August 2020

Executive Summary

This sixteenth annual report, presented to Parliament by the Child Death and Serious Injury Review Committee, provides highlights of the Committee's data analyses, reviews of child deaths, and activities undertaken to prevent the death or serious injury of children and young people in similar circumstances.

Of note in this report is the further decrease in the number and rate of child deaths. In 2019, the number of deaths of children and young people was the lowest recorded for fifteen years. Subsequent analysis found this to be largely due to a reduction in neonatal deaths, although the number of births was not significantly lower than in previous years. In 2020, the number of deaths of children and young people decreased further. Many factors may have contributed to this decline, including the impact of the COVID-19 pandemic.

Over the 16-year reporting period to 2020:

- The rate of death for Aboriginal children and young people usually resident in South Australia was 66 deaths per 100,000. By comparison, the rate of death for non-Aboriginal children and young people was 27 deaths per 100,000.
- Sixty-eight percent of child deaths were attributed to illness and disease, and approximately two-thirds of these deaths were of infants less than one year of age.
- Twenty-two percent of children and young people who died were assigned disability status by the Committee. Families caring for children and young people with disability face significant challenges in accessing services and support for their children.
- Thirty-nine children aged 0–12 years have died in transport crashes in South Australia, with 64% of these children not properly restrained. Of this 64%, half were aged 7 to 12 years and seated in an adult seat, despite being less than 145 cm tall – the minimum height at which a person can safely use most adult car seats.

Recommendations made by the Committee as part of its reviews have included the need for the whole of Government to provide services that reduce the likelihood of parents experiencing the loss of their children – through death or the child's entry into state care.

In removing a child or young person from their family to the care of the state, the state is responsible for ensuring that the child or young person has better opportunities to live a safer and healthier life than might otherwise have been the case.

The Committee used its data to inform its submission to the draft of South Australia's Road Safety Strategy to 2031 regarding safe restraint of children in vehicles, and the lack of recognition of 'low speed runovers'. The Committee's research indicates that low speed runovers, which disproportionately involve large SUVs, may be increasing. Four such deaths occurred in 2019 in South Australia.

The Committee endeavours to present the findings of its analyses and reviews to all relevant government and non-government agencies to inform the development of policies and services that impact the lives of children, young people and their families.

Section One

1. Child Deaths South Australia 2005–2020

S37 – Functions of the Committee

(1) The functions of the Committee are –

a. to review cases in which children die or suffer serious injury with a view to identifying legislative or administrative means of preventing similar cases of death or serious injury in the future; and

b. to make, and monitor the implementation of, recommendations for avoiding preventable child death or serious injury; and

c. to maintain a database of child deaths and serious injuries and their circumstances and causes.

Children and Young People (Oversight and Advocacy Bodies) Act 2016

1.1. Analysis and review of child deaths

The intent of the Committee is to improve the safety and wellbeing of children and young people in South Australia. It does this by collecting information about the circumstances and causes of all child deaths in South Australia, analysing and reviewing this information, making recommendations to relevant agencies, and monitoring the implementation of those recommendations. The Committee reviews specific cases of child death, and from time to time also reviews and analyses information about serious injuries.

1.2. Rates and patterns of death

Opportunities for prevention and intervention to improve the safety and wellbeing of children and young people can be identified through the systematic collection and analysis of information about child deaths. Section 37 of the *Children and Young People (Oversight and Advocacy Bodies) Act 2016*[1] identifies those deaths as eligible for review if: (a) the incident resulting in the child's death or serious injury occurred in the state; or (b) the child was, at the time of the death or serious injury, ordinarily resident in the state.

As required by the Act, the Committee maintains a database of child deaths and serious injuries, to which it continually adds information that informs its analyses about rates and patterns of child death in South Australia. Figure 1[2] shows death rates for all children and young people who died in South Australia during the 16 years from 2005 to 2020, while Figure 2 shows death rates for children and young people who were usually resident in South Australia[3].

1 https://www.legislation.sa.gov.au/
2 For each figure in Section One, there is corresponding data available on Data.SA
3 During this 16 year period, the average yearly population of children and young people aged 0 to 17 was 356,741. For more information on how this number was calculated, see Section 3.1.3

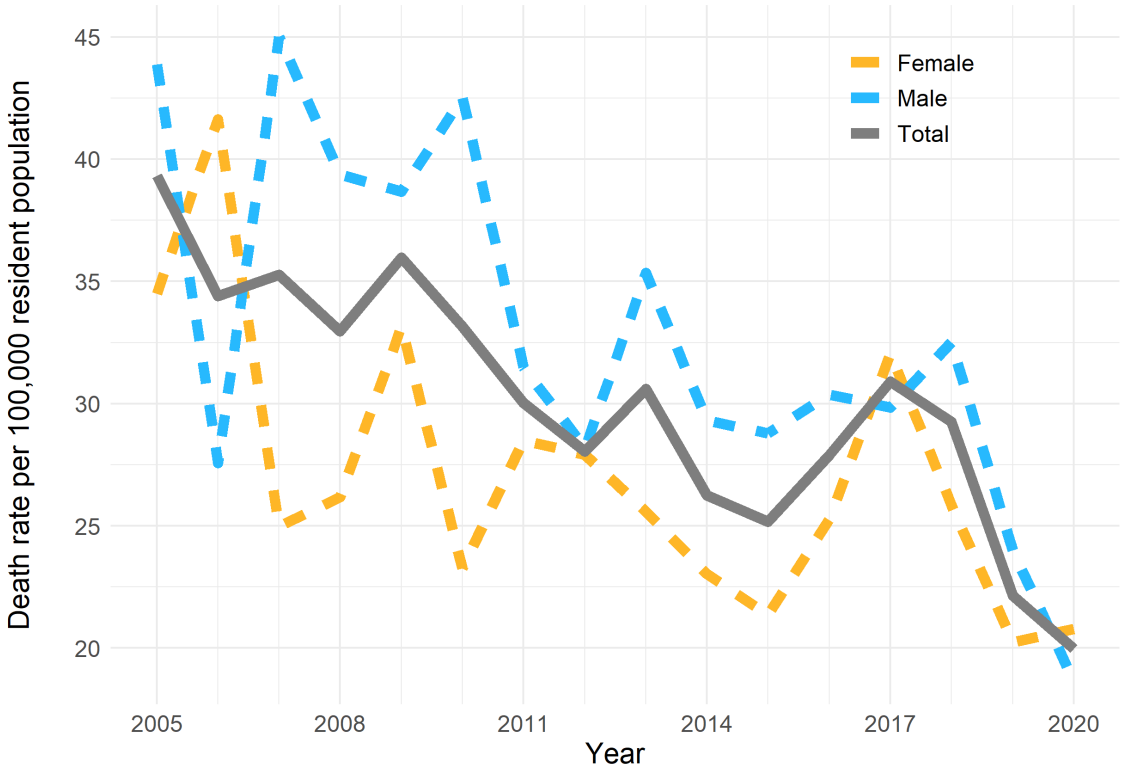

Figure 1: Death rate by year of death and sex for all children and young people, South Australia 2005–2020

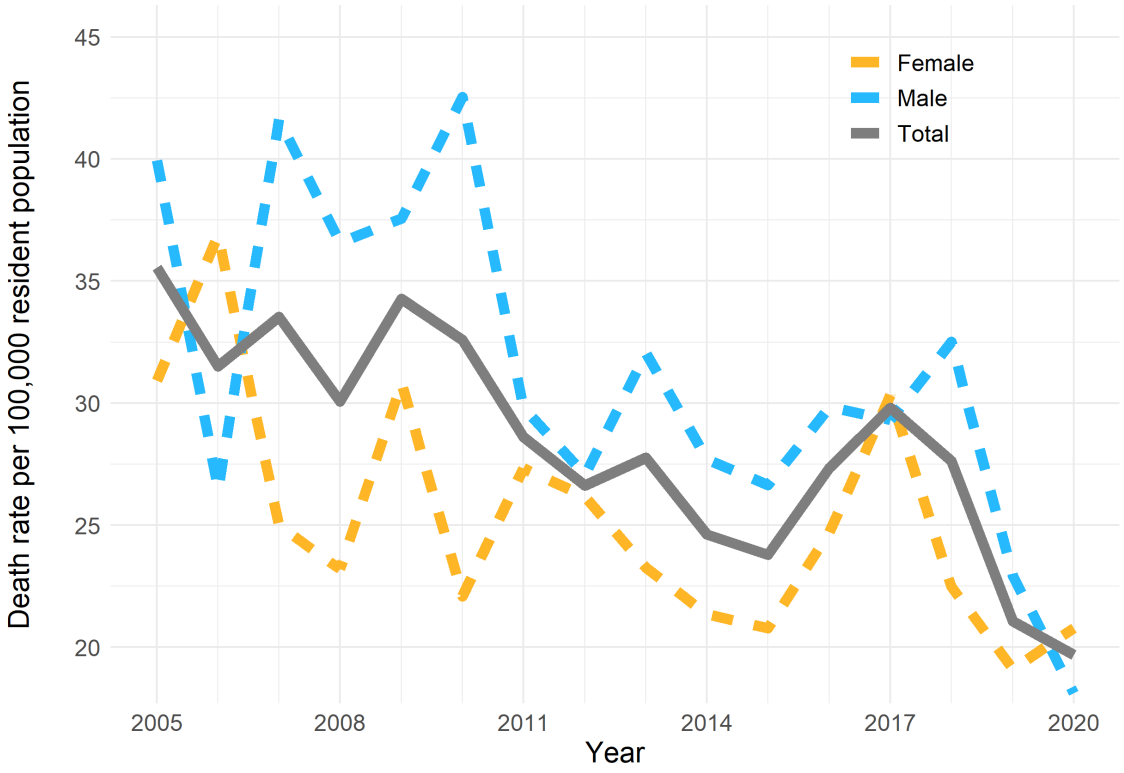

Figure 2: Death rate by year of death and sex for children and young people who were usually resident in South Australia, 2005–2020

As shown in Figures 1 and 2, there has been a long-term downward trend in the rate of death of children and young people in South Australia. In 2019, the Committee reported 81 deaths – the lowest on its record since 2005 and a substantial drop from previous years. As discussed in Section 1.7.1 of this report, this was due in part to a reduction in neonatal deaths. In 2020, there were 73 deaths. The reasons for this further drop are not yet clear and may include factors associated with the COVID-19 pandemic. The Committee will undertake further analysis to explore this issue.

1.2.1. Death rates by region

Important issues for service planning and delivery are highlighted when death rates and numbers of deaths are mapped against the South Australian Government's twelve administrative regions.

The highest *rate* of death for children and young people is associated with living in the Far North region of the state. In contrast, the greatest *number* of deaths is recorded in the Northern Adelaide region. Services should be planned to take into account regions where the rate of death is highest, and regions where the greatest number of deaths occur.

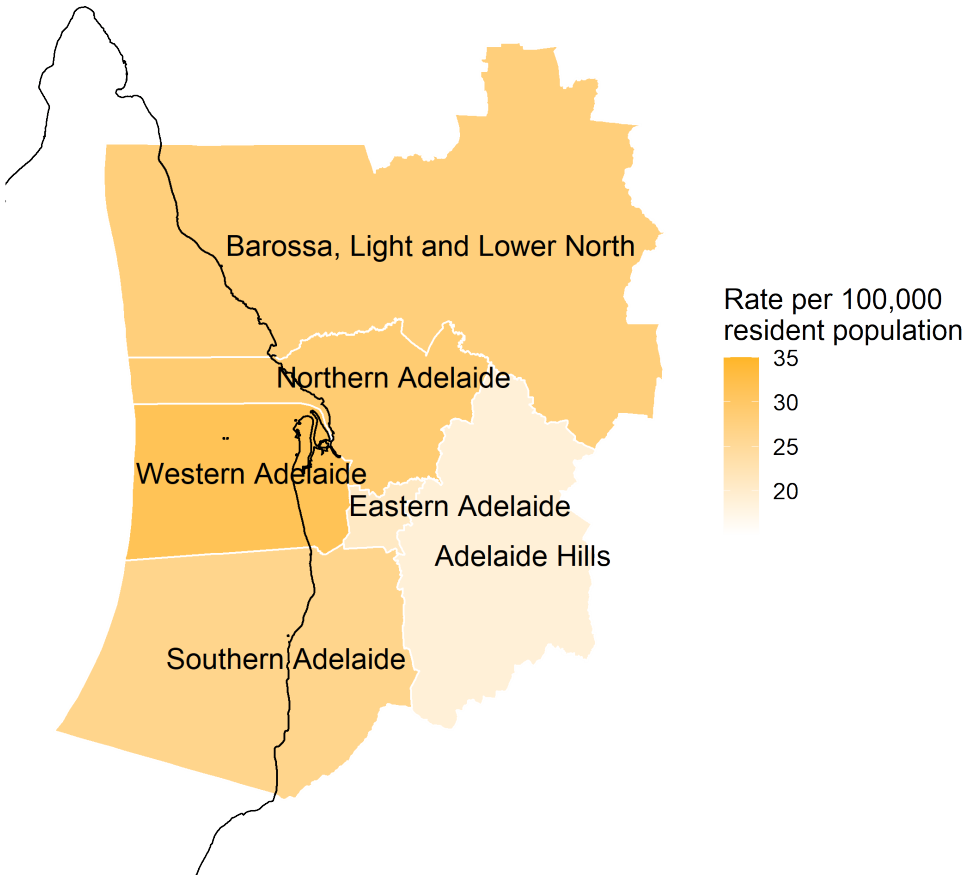

Figure 3: Death rate by metropolitan and inner rural regions for children and young people who were usually resident in South Australia, 2005–2020

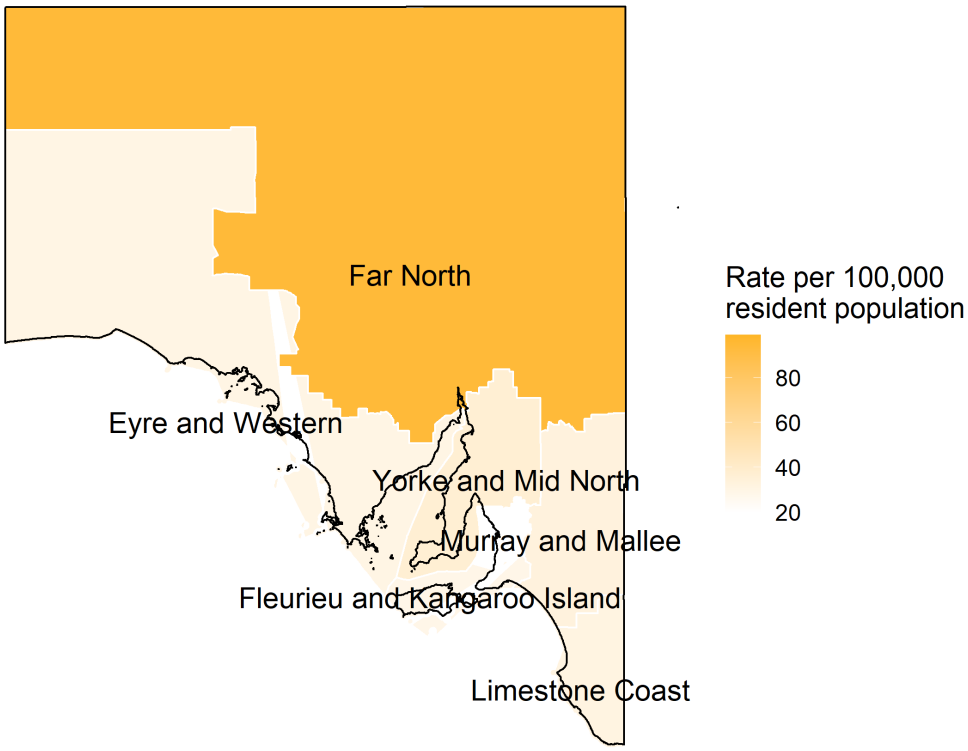

Figure 4: Death rate by outer rural regions for children and young people who were usually resident in South Australia, 2005–2020

1.2.2. Death rates of non-resident children and young people

Ninety-five (5.9%) of the 1712 children and young people who died in South Australia between 2005 and 2020 were usually resident in another state, territory, or country.

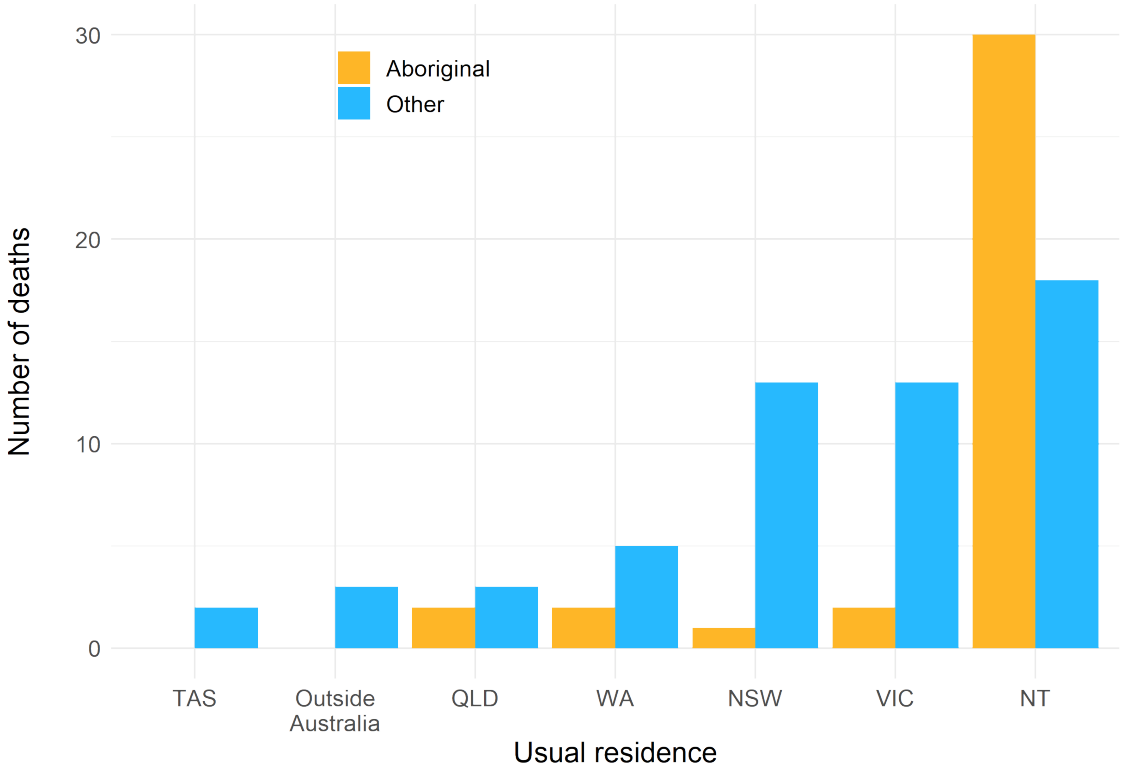

Figure 5: Number of deaths by state, territory or country of residence and cultural background, for children and young people not usually resident in South Australia, 2005–2020

Of the 95 non-resident children and young people who died in South Australia between 2005 and 2020, 48 were from the Northern Territory, and 30 of these 48 were Aboriginal children and young people.

Many of the deaths occurring in South Australia reflect cross-border arrangements where seriously ill children and young people are brought to Adelaide for treatment of complex medical conditions associated with extreme prematurity, infant and childhood illness, and various external causes.

On average, five non-resident children die in South Australia each year. Only one non-resident child died in South Australia in 2020, possibly reflecting reduced interstate and international travel due to the COVID-19 pandemic.

1.2.3. Death rates and socioeconomic disadvantage

More children and young people die in areas of South Australia where there are greater levels of socioeconomic disadvantage[4]. The relationship between child deaths and socioeconomic disadvantage is shown in Figure 6. Deaths of all children and young people between 2005 and 2020, resident and non-resident, were included in this analysis.

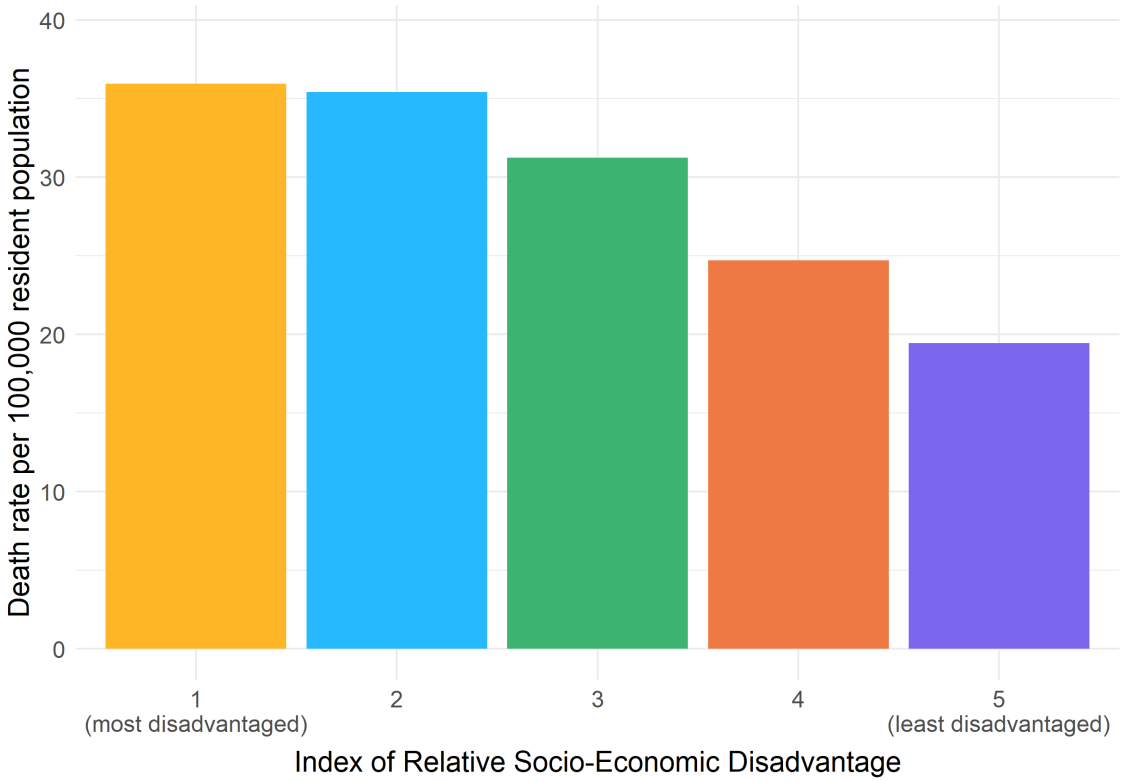

Figure 6: Death rate by Index of Relative Socio-Economic Disadvantage for all children and young people who died in South Australia, 2005–2020

[4] *For information on how socioeconomic disadvantage is defined and used in this Annual Report see Section 3.1.4*

1.3. Deaths of children and young people and the child protection system

The Committee continues to review deaths of children and young people where a child, young person, or their family had had contact with the Department for Child Protection (DCP) in the three years prior to death. The intent is to monitor the implementation of recommendations associated with these reviews, and to analyse the number and causes of deaths.

In the 16 years from 2005 to 2020, 473 (28%) of the 1712 children and young people who died, or their families, had had contact with the child protection system. Of these 473 children and young people, 227 (48%) lived in the state's most disadvantaged areas[5].

1.4. Deaths of infants and children whose parents had been in state care

The Committee reviewed the life circumstances of seven parents (four women aged 23–36 years, and three men aged 24–29 years), focusing on their life circumstances at the time of their infant's death.

This was the Committee's third review of parents who, at some point in their own childhood, have been placed in state care[6] and subsequently had an infant who died. Each review has documented a different aspect of this experience: the issues that led to the parent's placement in care, their experiences in care, and the impact that these experiences had on their life trajectories.

In the Committee's view, measures are needed to acknowledge and address the challenges that arise in the lives of these parents, including:

- experiences of abuse, neglect and cumulative harm
- socioeconomic deprivation, reflected in unemployment, poverty and housing instability
- mental and physical health problems

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[5] As represented by postcodes within the lowest relative disadvantage SEIFA quintile within South Australia. For more information on how socioeconomic disadvantage is defined and used in this Annual Report see Section 3.1.4.
[6] For the purposes of this review the Committee defines 'in state care' as any period of time when the child or young person was placed under the Guardianship of the Minister.

- violent and aggressive ways of relating that may result in perpetrating, and/or being the victim of, severe and frequent domestic violence
- damaged relationships
- the death of a child and/or the loss of a child(ren) taken into state care.

Of note is that the circumstances of these parents' lives reflect the results of several other recently published research studies[7]. The studies provide compelling evidence of poor outcomes for children and young people who have experienced state care, and their infants. For example, a retrospective cohort study of all persons born in South Australia between 1986 and 2003 found that by 33 years of age, the death rate for those who had at least one out-of-home-care placement was 30.9 per 1000, compared to 5.1 per 1000 for those with no child protection system contact[8].

The Committee notes the policies and programs referred to in the South Australian Government's 2020 Annual Report *Safe and Well: supporting families, protecting children,* which have been designed to improve the short and long-term outcomes for children and young people placed in state care and, in particular, for those young people who are facing the challenge of 'transitioning out' of state care.

The Committee submitted this review and its associated recommendations to the Minister for Education. The Committee invited a response to its recommendations from the Ministers for Child Protection, Health and Wellbeing, and Human Services. At the time of writing, a reply had been received from the Minister for Human Services (Table 1). The Committee acknowledges that the reforms being undertaken by the Department of Human Services have the potential to positively impact the life trajectories of parents such as those who were the subject of its reviews, but remains concerned about the availability of sufficient funding and resources to meet the demand for these services.

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[7] *Segal L, Armfield J, Gnanamanickman D, Preen D, Brown D and Nguyen H (2021) Child maltreatment and mortality in young adults. Pediatrics, 147https://pubmed.ncbi.nlm.nih.gov/33318224/*
Armfield J, Gnanamanickman D, Johnston D, Brown D, Nguyen H and Segal L. Intergenerational transmission of child maltreatment in South Australia: a retrospective cohort study. Lancet 2021 https://reader.elsevier.com/reader/sd/pii/S2468266721000244?token=CC7C7834EA3CAB43BB54143DC899824F0682CC711D0A37375BF34D2D9E4403596011020EACB457CAB449149775447241&originRegion=us-east-1&originCreation=20210511022238

[8] *Ibid*

Table 1: Recommendations and responses from a review into the deaths of infants and children whose parents had experienced being in state care

Recommendations and responses
Responses to recommendations were invited from the Ministers for Child Protection, Health and Wellbeing, and Human Services. **Recommendation 1** Services across the whole of government must be provided that reduce the likelihood parents will experience the loss of their children – through death, or the child's entry into state care – by: - recognising key triggers for service provision, eg, notification of an unborn child concern - ameliorating the trauma experienced by children and young people who enter state care through evidence-based, trauma-informed programs - making provision for more comprehensive support of young people as they transition from state care - continuing to prioritise the service needs of these young people in early adulthood and as they become parents - equipping these young parents to participate in society as equal, contributing and valued citizens.
Response, Minister for Human Services *Child and Family Support Systems (CFSS) reform strategies aligning with this recommendation include:* - *establishment of a referral management service for families with children at high risk that assesses the family's needs and matches them to the most appropriate services. Infants subject to unborn child concern notifications and parents who have been in state care are considered in the assessment of risk.* - *intensive support programs for young parents who have, or are at risk of having, children placed in state care* - *building workforce capability with skills that emphasise trauma responsive and culturally informed approaches coupled with assertive engagement.*
Recommendation 2 Investment in independent research that tracks the long-term outcomes for children and young people who have experienced state care.
Response, Minister for Human Services *This department will be investing in university research that 'deepens understanding' about service needs and approaches for young people who have experienced trauma and that monitors the outcomes of its CFSS programs.*

1.5. Deaths of Aboriginal children and young people

During the period 2005 to 2020, Aboriginal children and young people constituted 4.4% of the South Australian population of children and young people, but they accounted for 12% of child deaths. The rate of death for all Aboriginal children and young people who died in South Australia was 82 deaths per 100,000. For Aboriginal children and young people who were usually resident in South Australia, the death rate was 66 deaths per 100,000 over the same period (Figure 7). This difference in rates reflects the number of children and young people with complex medical conditions who were retrieved from other states or territories for treatment in South Australian hospitals (see Section 1.2.2). The rate of death for non-Aboriginal children and young people was 28 deaths per 100,000. The rate of death for non-Aboriginal children and young people usually resident in South Australia was 27 deaths per 100,000[9].

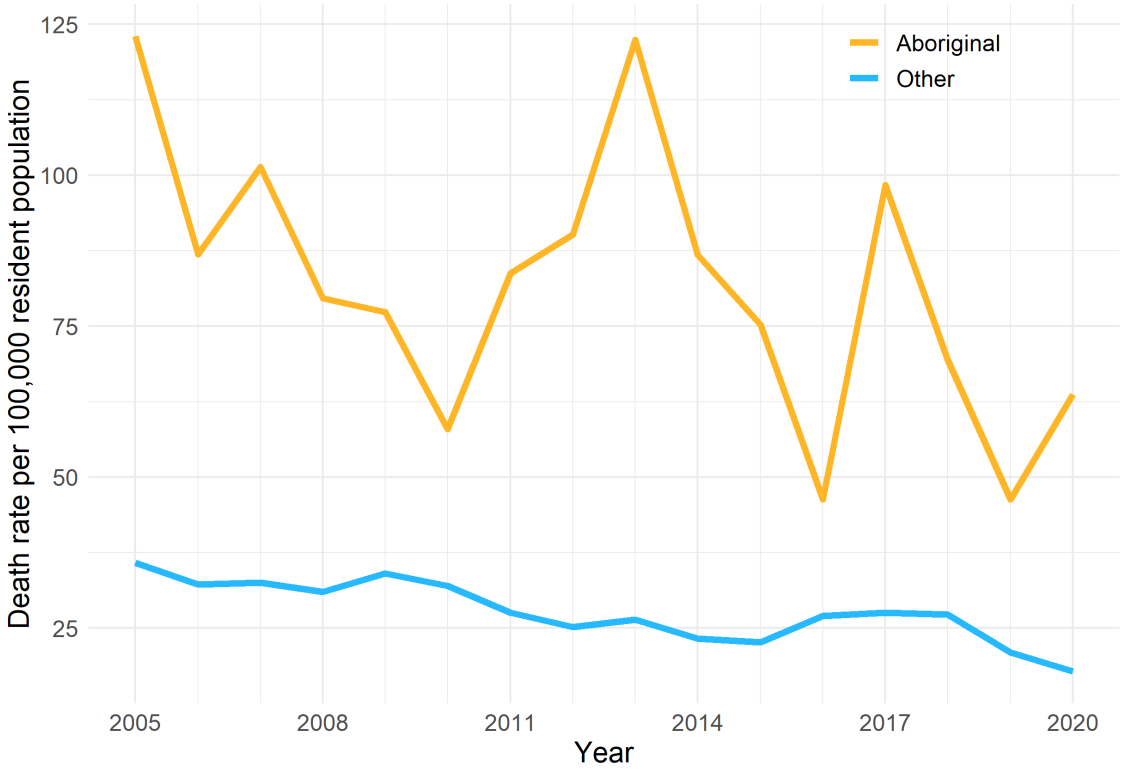

Figure 7: Death rate by cultural background for all children and young people, South Australia 2005–2020

[9] *For information about the estimated population of Aboriginal children in South Australia see Section 3.1.3.*

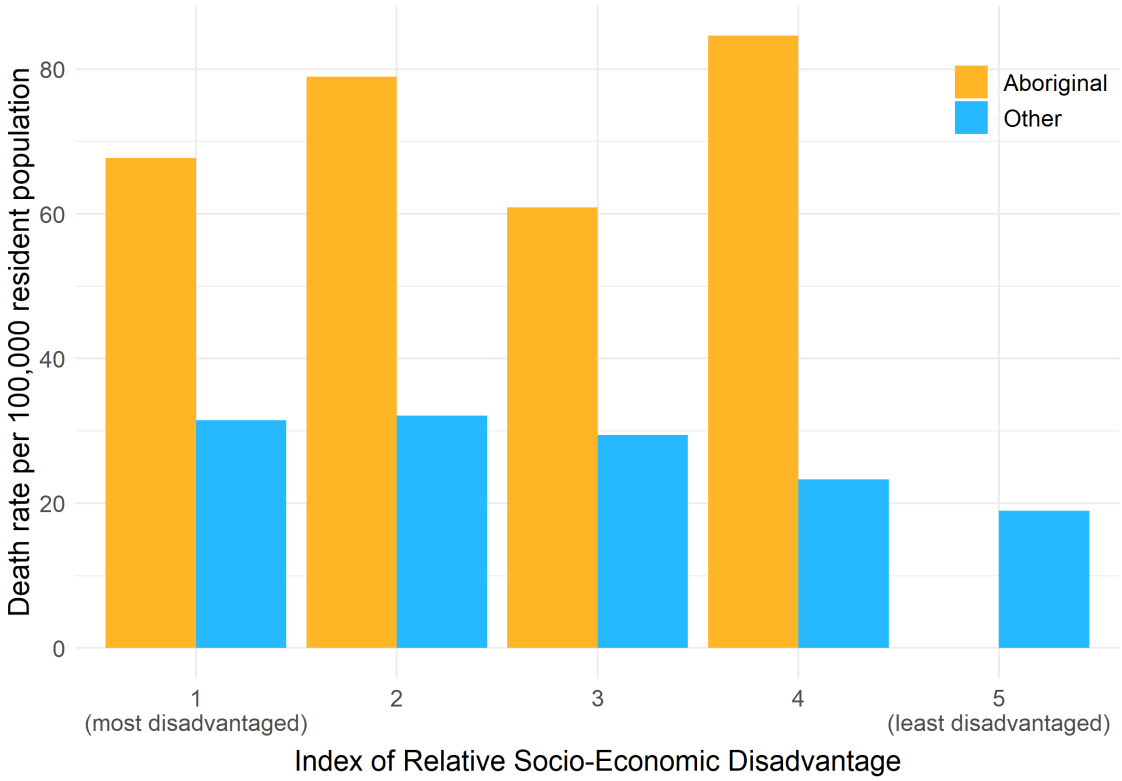

Figure 8: Death rate by cultural background and socioeconomic disadvantage, South Australia 2005–2020

Figure 8 shows the death rate for Aboriginal and non-Aboriginal children and young people in each Index of Relative Socio-Economic Disadvantage quintile. The death rate for Aboriginal children and young people is significantly greater than for their non-Aboriginal peers, regardless of the level of socioeconomic disadvantage they experience. Note that the death rate for Aboriginal children and young people in the least disadvantaged areas has not been calculated because fewer than three deaths were recorded.

1.6. Deaths of children and young people with disability

Families caring for children with a disability face significant challenges in accessing services and support for their children. Information about the deaths of all children and young people in South Australia is reviewed by the Committee to determine whether a child or young person's daily activities had been significantly limited by disability, and to explore connections between the disability and their subsequent death.

During the period 2005 to 2020, 379 of the 1712 (22%) children and young people who died were assigned disability status by the Committee[10]. On average, 24 children and young people who died have been assigned disability status each year.

In 2020, a review was submitted about the deaths of children and young people with disability who were placed in the care of others[11]. The review was based on the view that all children and young people, when placed in the care of others, are entitled to be kept safe and to have their needs understood and met. The Committee concluded that to prevent similar deaths, the quality and safety standards governing the practices of agencies who provide care for children and young people with disabilities must ensure that the most up-to-date information about that child or young person's care needs is provided to them. Only then can a decision be made about the capacity of a facility to accommodate those needs, in terms of the level of staffing, the experience and training of staff, the physical amenities of the facility, and the available equipment.

The Committee's recommendations were brought to the attention of key state and national agencies who hold responsibilities for the safety and wellbeing of children and young people with disabilities. A response was sent to the Committee on behalf of the NDIS Quality and Safeguards Commissioner which noted that the *National Disability Insurance Scheme (Provider Registration and Practice Standards) Rules 2018* are subject to regular review and the Committee's recommendations would be given detailed consideration in that context. A successful meeting was held with the State Director of the NDIS' Quality and Safeguards Commission. The Committee will continue to provide its recommendations about improvements to safety and quality standards to the state body.

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[10] *See Section 3.2.4 for the Committee's definition of disability status.*
[11] *Child Death and Serious Injury Review Committee Annual Report 2019-20, Section 1.5.1 https://cdsirc.sa.gov.au/annual-report-2019-20/Chapter-1.html#1.5.1*

1.7. Infant mortality

Of the 1712 children and young people who died in South Australia between 2005 and 2020, 967 (56%) were infants under one year of age.

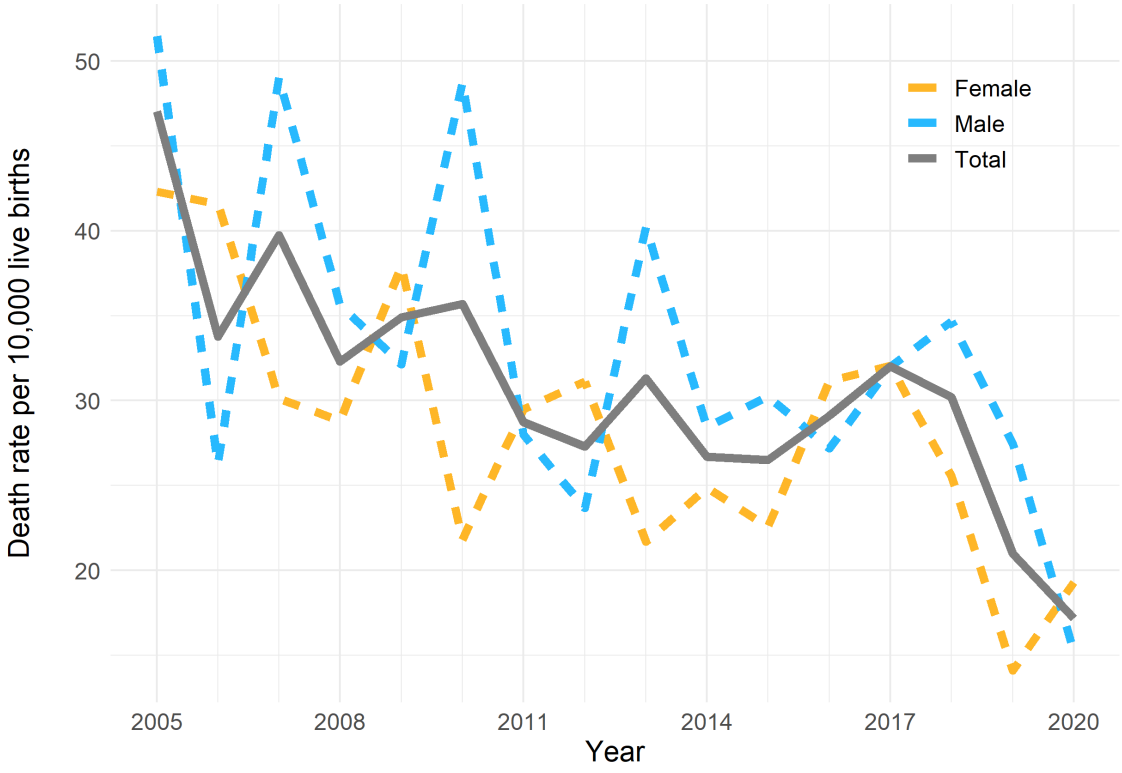

Figure 9: Death rate per 10,000 live births by year of death and sex, for infants, South Australia 2005–2020

As an official count of live births in 2020 is not yet available, the 2020 infant death rates shown in Figure 9 are calculated using predicted live birth counts[12]. These rates are therefore subject to change. For example, if COVID-19 has contributed to a decreased birth rate in South Australia, as it has in parts of Europe and the United States[13], then the infant death rate would be higher than reported here. The Committee will monitor this data and report any significant changes.

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[12] See Section 3.1.2 for details about how the predicted live birth count was calculated.
[13] Aassve A, Cavalli N, Mencarini L, Plach S, Sanders S. (2021) Early assessment of the relationship between the COVID-19 pandemic and births in high-income countries. PNAS, 118 (36) e2105709118; DOI: 10.1073/pnas.2105709118

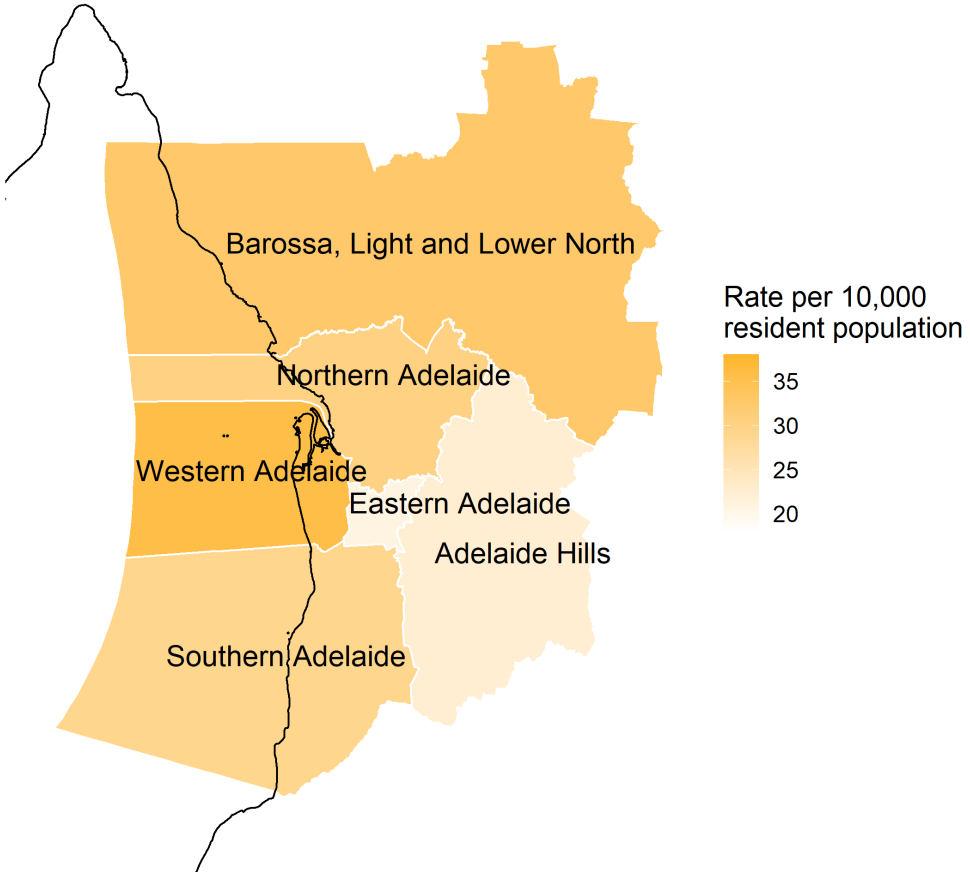

Figure 10: Death rate by metropolitan and inner rural regions for infants who were usually resident in South Australia, 2005–2020

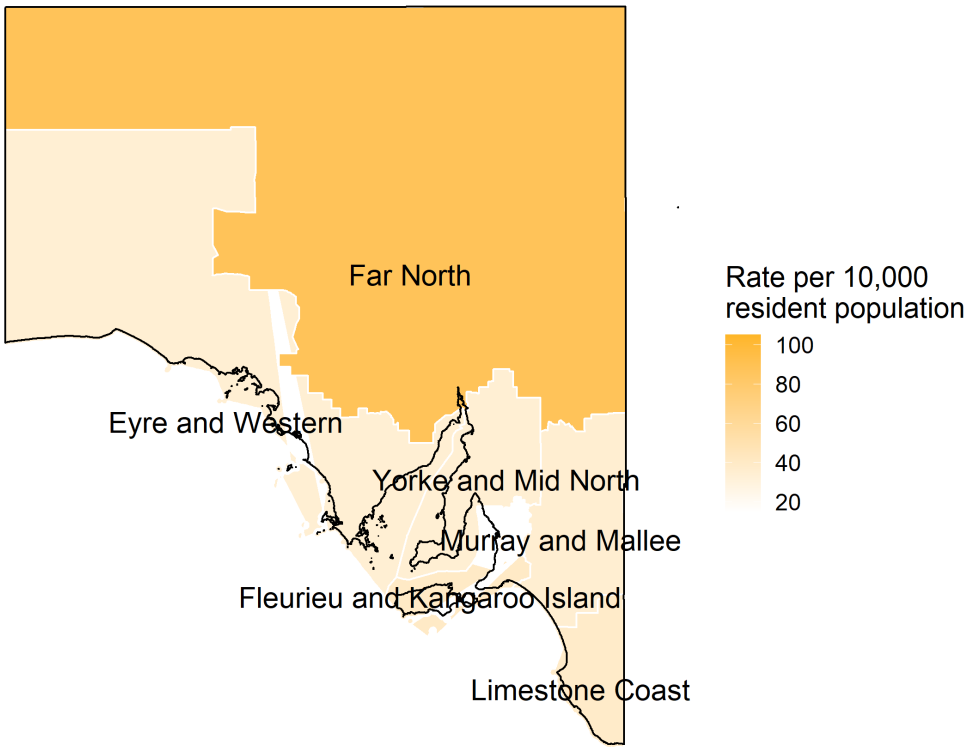

Figure 11: Death rate by outer rural regions for infants who were usually resident in South Australia, 2005–2020

Figure 11 shows that the highest death *rate* occurred in the Far North region. However, from the perspective of service delivery, it is important to note that the highest *number* of deaths occurred in the Northern Adelaide region.

1.7.1. A reduction in neonatal deaths 2005–2019

In 2019, the Committee recorded the lowest number of infant deaths and the lowest infant death rate to date for the past 15 years. This was found to be largely due to a smaller number of neonatal deaths. Fourteen fewer neonates died compared with the previous 5-year average – a reduction of 37%.

The number of infants born in 2019 was not significantly lower than in previous years.

Figure 12 shows the results of an analysis of causes of death for neonates, comparing 2019 causes to the average over the previous five years by ICD-10 code block. The Committee's blog post explores these issues in more detail[14].

[14] https://cdsirc.sa.gov.au/why-were-there-fewer-neonatal-deaths-in-2019/

Significantly, in 2019, there were no deaths attributed to 'Disorders related to length of gestation and fetal growth' (block P05-P08)[15]. In previous years, these codes represented the second most common causes of death, accounting for an average of seven deaths per year. These deaths don't appear to have been 'pushed' into other blocks, since there were no increases in the number of deaths in other blocks in 2019, with the exception of a small jump in block P00-P04.

The reasons for the reduction in deaths from the causes represented by these code blocks are likely to be multifactorial and complex.

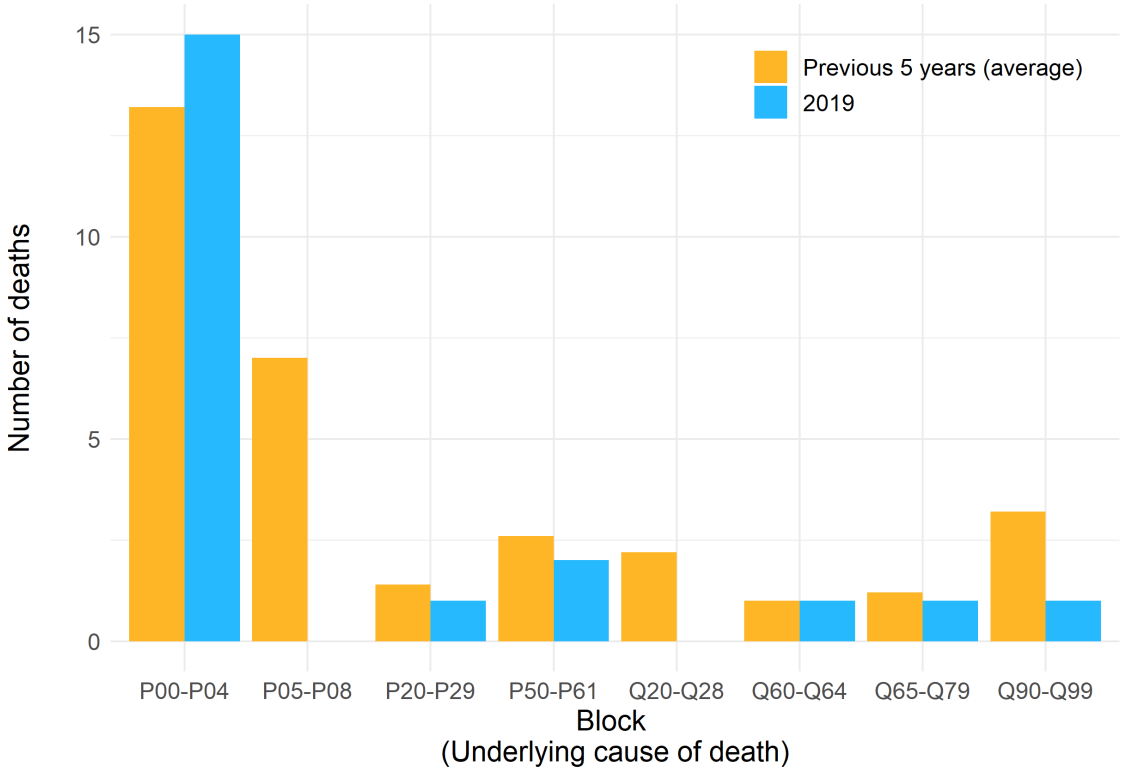

Figure 12: Number of neonatal deaths in the most commonly occurring ICD-10 code blocks, 2019 vs previous 5-year average

Referring back to Figure 9, the infant death rate – and the number of infant deaths – decreased further still in 2020. However, as COVID-19 has since introduced potential factors influencing birth rates and infant and neonatal mortality, this analysis has not been extended into 2020. The Committee will continue to monitor and explore these issues.

[15] *See Section 3.3.1 for further information about this analysis.*

1.7.2. Sleep-related infant deaths and socioeconomic disadvantage

On average, 13 infants die suddenly and unexpectedly each year in South Australia. Most of these deaths occur in the infants' sleep environments, and in almost all cases at least one safe sleeping risk factor is identified. These risk factors are not necessarily causes of death in their own right, but rather behaviours or situations that increase the risk of infants dying after being placed to sleep – and they can be eliminated with education about, and adoption of, safe sleeping practices[16].

Through prevention campaigns by organisations including Red Nose, Kidsafe SA, and SA Health, the number of infant deaths involving safe sleeping risks has declined over the past sixteen years. However, unsafe infant sleep practices, including unsafe bedding and bed-sharing, are still common and continue to contribute to the deaths of infants.

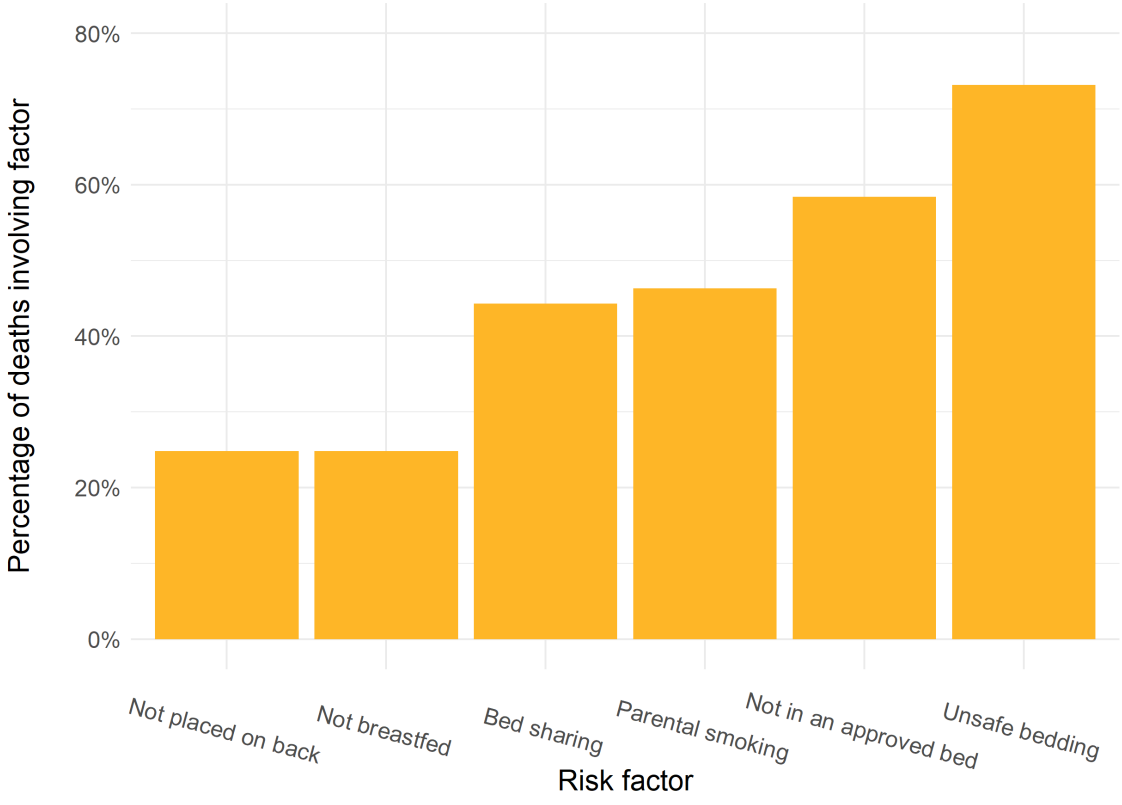

Figure 13: Percentage of sleep-related infant deaths involving each safe sleeping risk factor, South Australia 2005–2020

[16] *https://kidsafesa.com.au/safe-infant-sleeping/*

The most common risk factor identified in sleep-related infant deaths – unsafe bedding – refers to any loose items present in the infant's sleep environment. When placing an infant to sleep, it is important to ensure there are no suffocation hazards in the cot, including toys, pillows, and loose blankets. During the period 2005 to 2020, unsafe bedding was present in approximately three-quarters of all sleep-related infant deaths in South Australia (Figure 13).

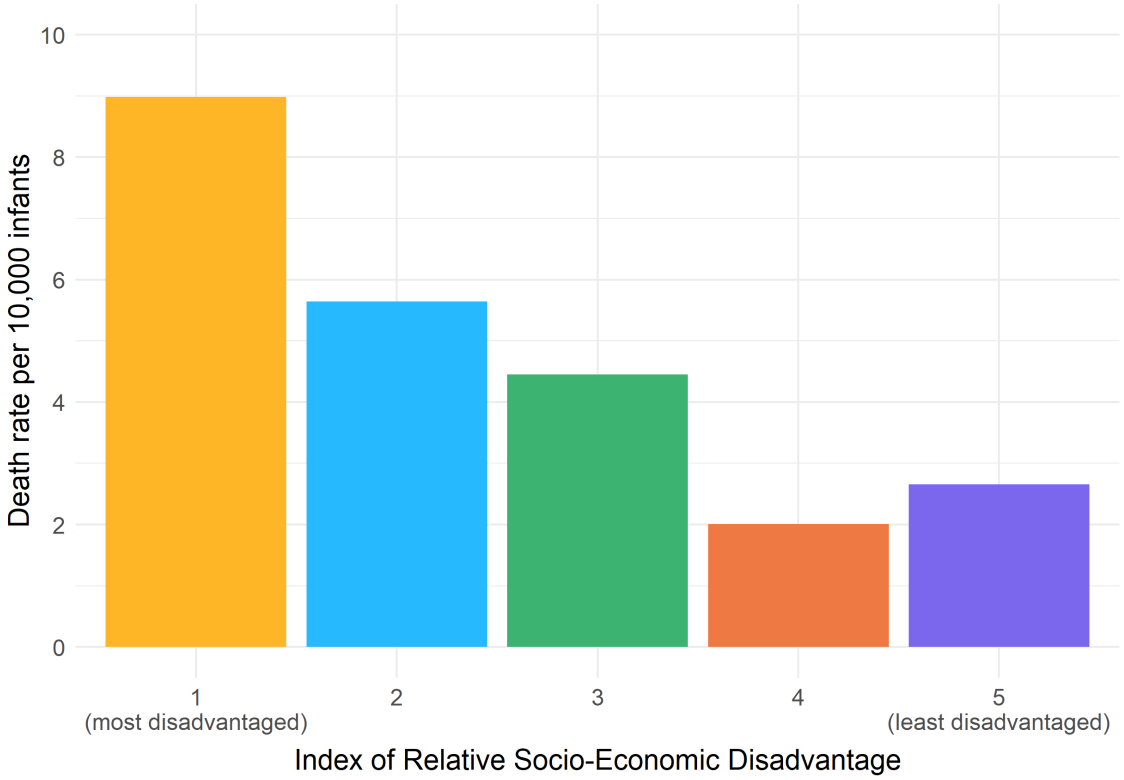

Figure 14: Rate of sleep-related infant death by Index of Relative Socio-Economic Disadvantage, South Australia 2005–2020

Almost half of all sleep-related infant deaths occurred in the state's most socioeconomically disadvantaged areas. Infants in these areas were four times as likely to die suddenly and unexpectedly than infants who lived in the least disadvantaged areas (Figure 14). Many of these areas are located in the Northern Adelaide region.

The decline in infant deaths over the years indicates that prevention messaging and education are effective – but there is a need to continue targeted efforts to prevent

sleep-related infant deaths. See the Committee's blog post for a more detailed analysis of sleep-related infant deaths[17].

Preventing sudden unexpected infant deaths – forum

In April 2021, the Committee and Kidsafe SA co-hosted a forum for agencies involved in managing service provision to vulnerable families and/or safe sleeping intervention and prevention. The focus of the forum was to:

- ensure that there is awareness of effort (ie, who is doing what)
- share information about what works and why
- explore opportunities for collaboration
- identify gaps in service provision and/or orientation
- agree to future steps.

At the conclusion of the forum, there was general agreement about the strength of universal prevention efforts, but also awareness about the need to focus on vulnerable families with targeted messaging and perhaps the identification of champions that different communities would recognise, relate to, and listen to. The group identified 'touch points' on the antenatal journey and could see a strong evidence-base emerging that supports the introduction of the Pēpi-Pod program to help prevent the sudden unexpected deaths of infants.

To progress co-ordinated prevention efforts, the Committee and Kidsafe SA have held discussions with Wellbeing SA about the development of a policy environment for the prevention of sudden unexpected deaths of infants (SUDI).

[17] *https://cdsirc.sa.gov.au/sleep-related-infant-deaths-and-socio-economic-disadvantage/*

1.8. Deaths from illness or disease

During the period 2005–20, 1166 (68%) of the child deaths in South Australia were attributed to illness or disease. The majority (68%) of these deaths were of infants under one year of age and were associated with problems related to labour and delivery, chromosomal abnormalities, and congenital conditions without a precisely known cause.

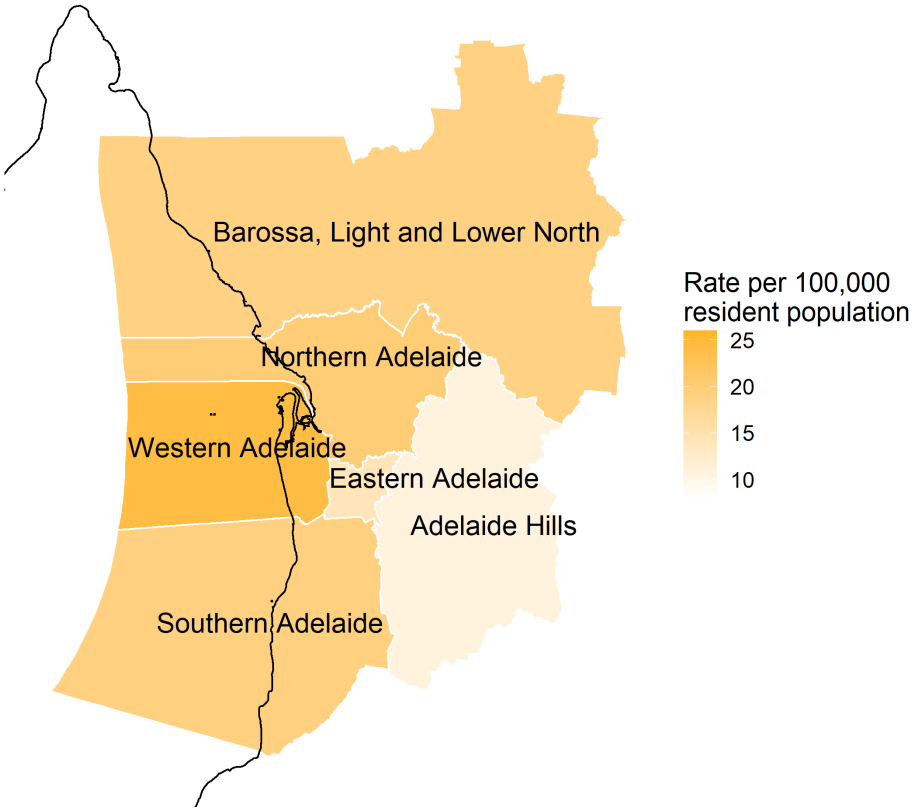

Figure 15: Death rate by metropolitan and inner rural regions for children and young people whose deaths were attributed to illness or disease, and who were usually resident in South Australia, 2005–2020

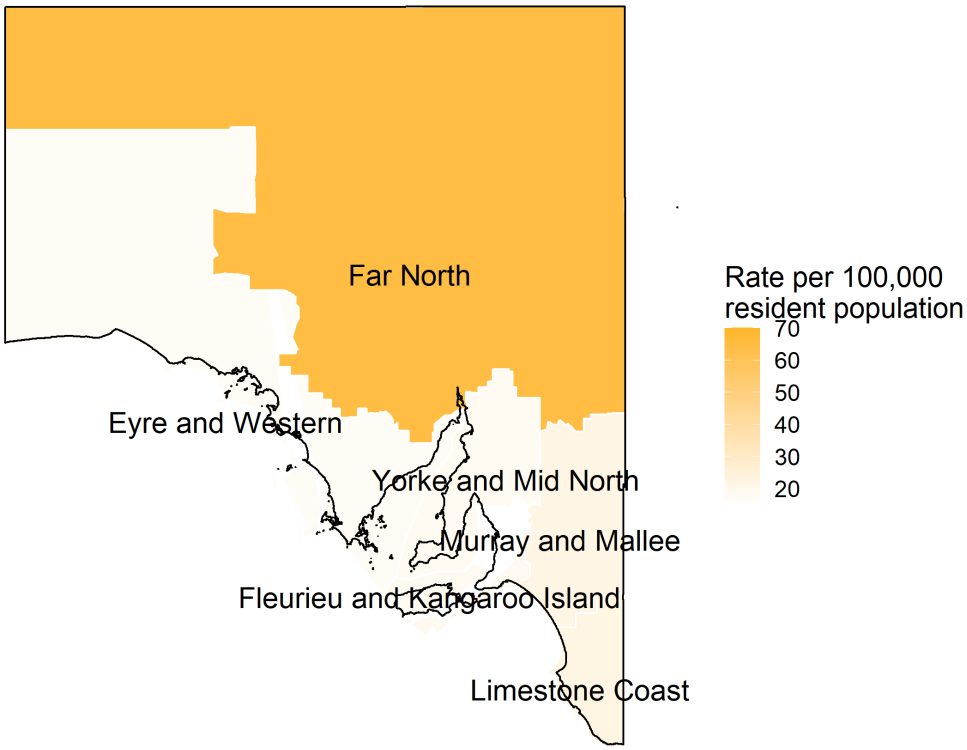

Figure 16: Death rate by outer rural regions for children and young people whose deaths were attributed to illness or disease, and who were usually resident in South Australia, 2005–2020

1.8.1. Policy direction and chronic disease management

The Committee has continued to advocate for children experiencing lifelong chronic illness. Feedback was provided to SA Health's consultation on the Women's, Child and Youth Health Plan 2021–31 Summary Framework. The Plan prioritises service delivery to children, young people and families at risk, within its focus on all children and young people.

The Committee's feedback emphasised the need for the Plan to have a focus on effective collaboration between SA Health, the Departments for Education and Child Protection, the Department of Human Services, and other relevant agencies to better support children experiencing lifelong chronic disease or disability. Such collaboration should take into account an understanding of research findings, consumer input, and policy development, and aim to include specific approaches to care coordination such as the Team Around the Child.

The Committee also recommended that the Plan address transition from paediatric to adult health care for children experiencing chronic health issues and suggested that families with diverse cultural or linguistic backgrounds continue to be prioritised within SA Health's Plan for services from 2021–31.

The Committee met with the Child Protection Service of the Women's and Children's Health Network to discuss the neglect of critical medical care in families experiencing both high care needs and psychosocial complexity. The Committee noted that recognition of the neglect of critical medical care included factors of chronic non-attendance for health care, and the lack of identification of a family's capacity to provide for a child's complex care needs.

The Committee raised the benefits of generalist medical leadership in the management of complex chronic disease and early parenting capacity assessments. The Committee will progress its work on neglect of critical medical care with service systems in 2022.

1.9. Deaths from external causes

Deaths from external causes are those deaths that the Committee has classified as: transport-related, suicide, drowning, a deliberate act by another person, fire-related, accidents (falls, suffocation and asphyxiation, poisoning), neglect, and health-system related[18].

[18] *For the Committee's categories of death, see Section 3.2.3*

1.9.1. The number and causes of deaths attributed to external causes

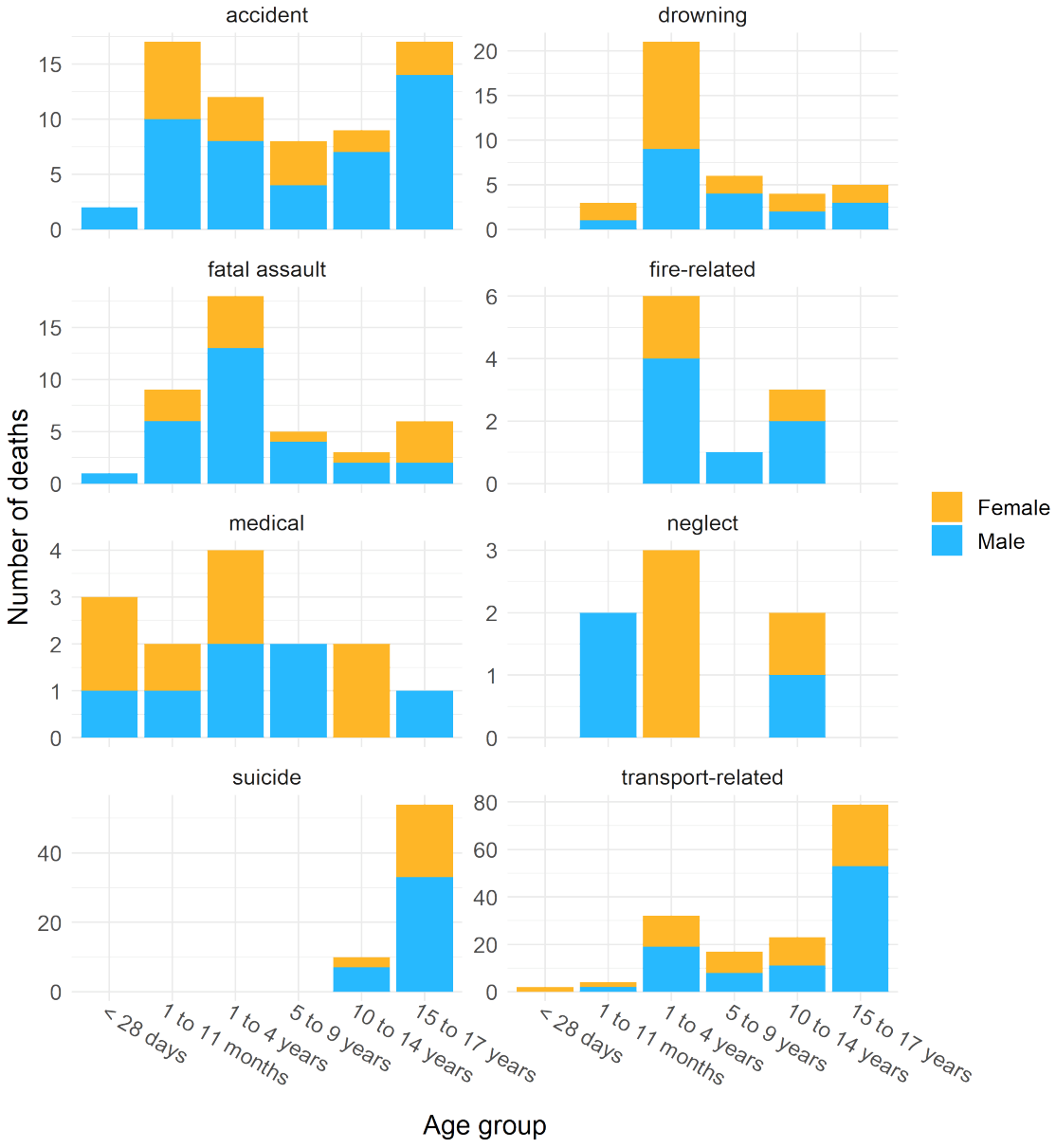

Figure 17: Number of deaths from external causes by age group, sex, and category of death for all children, South Australia 2005–2020. Note that y-axis ranges are different for each subplot.

1.9.2. Deaths of children aged 0 to 12 years who were passengers in transport crashes

Between 2005 and 2020, 39 children aged 0 to 12 years died as passengers in transport crashes in South Australia. Twenty-five (64%) of these children were not appropriately restrained, including nine children who were unrestrained (Figure 18). Of these 25 children, half were aged 7 to 12 years and seated in an adult seat despite being less than 145 cm tall – the minimum height at which a person can safely use most adult car seats[19].

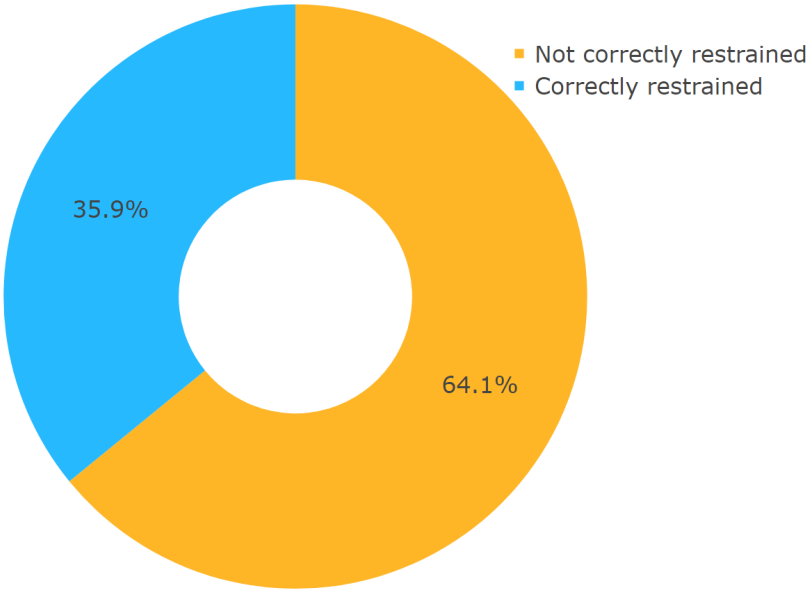

Figure 18: Percentage of deaths of children aged 12 years and under who were passengers in vehicles and who were correctly restrained or not correctly restrained, South Australia 2005–2020

These data suggest that a principal issue is the lack of understanding of, and compliance with, safe child restraint practices. The law implies that most children can safely be transitioned to an adult seat when they reach seven years of age. However, most children are not large enough to do so safely until they are 10 to 12 years old. Only one in approximately 14,000 children reach 145 cm by age seven. This nuance is not explained on Government road transport information websites[20].

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[19] *Neuroscience Research Australia and Kidsafe Australia: Best Practice Guidelines for the Safe Restraint of Children Travelling in Motor Vehicles, 2nd Edition. Sydney: 2020*
https://www.childcarseats.com.au/legal-requirements
[20] *https://www.mylicence.sa.gov.au/road-rules/seatbelts-and-child-restraints;*
https://www.sa.gov.au/topics/driving-and-transport/roads-and-traffic/seatbelts-and-child-restraints

On the *mylicence* website, it is suggested that children *should* remain in a booster seat until they are 145 cm, but it is not stated as a requirement.

The Committee used these data to inform a submission to the draft of *South Australia's Road Safety Strategy to 2031*[21] (the Strategy). The Committee expressed its concern that the Strategy, while acknowledging the use of child restraints as a target area, did not include any specific strategies, nor include any information on the issue of children prematurely transitioning to adult seats.

The Committee also queried the lack of recognition of 'low-speed runovers' in the Strategy. Deaths resulting from low-speed runovers involve infants and toddlers and usually occur at the child's home with a parent as driver. Research by the Committee indicates that low-speed runovers, which disproportionately involve large SUVs, may be increasing. Four of these deaths occurred in 2019 alone in South Australia.

While these deaths do not occur on public roads, they are nevertheless road transport-related. In the Committee's view, South Australia's Road Safety Strategy should reflect this and protect South Australia's youngest road users. Altering road user behaviour and promoting the use of safer vehicles are both key strategic focus areas in the Strategy and could contribute to the prevention of these deaths.

To inform future prevention efforts, the Committee will continue to collect and analyse data on deaths in similar circumstances.

1.9.3. Deaths attributed to drowning

Thirty-nine children and young people drowned in South Australia between 2005 and 2020, an average of 2.4 deaths per year. The average yearly number of drowning deaths has not decreased over time[22].

Most drownings involve children aged 1 to 4 years and occur in private pools (Figure 19). Pool-related drownings are the most common type of drowning death – often involving non-compliant pool fencing, open or unlocked gates, and lapses in supervision. There were 16 such deaths in South Australia between 2005 and 2020.

About a quarter of the drowning deaths of children aged 1 to 4 years occur due to incidents involving bathtubs or other small bodies of water.

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[21] *https://yoursay.sa.gov.au/road-safety*
[22] *https://cdsirc.sa.gov.au/deaths-of-children-due-to-drowning/*

School-aged children and young people (5 to 17 years) most commonly drown at the beach. Four of nine beach drownings occurred at the Glenelg breakwater known as 'the groyne'.

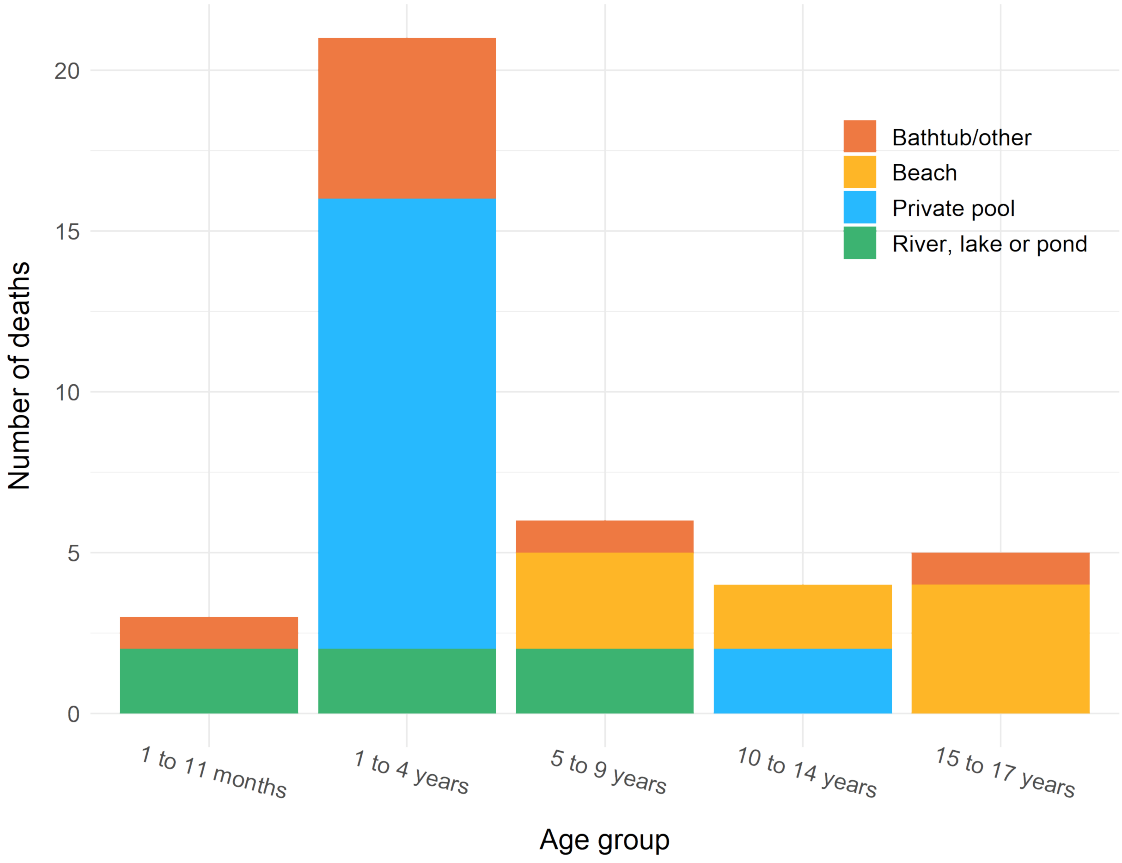

Figure 19: Number of deaths by age group and drowning category, South Australia 2005–2020

Influence of cultural and linguistic background

Research suggests that people from culturally and linguistically diverse backgrounds are at greater risk of drowning[23]. Three of the four deaths occurring at 'the groyne' involved children and young people with diverse cultural and linguistic backgrounds. The risk factors identified in these deaths were generally poor swimming ability and lack of understanding of the danger of rips, waves, and other ocean conditions. Although these risk factors may be associated with culturally or linguistically diverse backgrounds, they are not unique to these groups.

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[23] *Willcox-Pidgeon SM, Franklin RC, Leggat PA, et al. Identifying a gap in drowning prevention: high-risk populations. Injury Prevention 2020;* ***26:****279-288.*

Summary and opportunity for prevention

The Committee will continue to contribute to the prevention of childhood drowning through engagement with key stakeholders in relation to the following issues:

- Water safety campaigns, especially those focusing on domestic swimming pool safety, inflatable swimming pools, and provision of water safety programs – Kidsafe SA, Royal Life Saving SA, Surf Life Saving SA and the Office of Consumer and Business Services
- Legislative changes to promote swimming pool registration and regular pool maintenance inspections, with a focus on the role and responsibilities of local government – Attorney General's Department and local government councils
- Changes to safety signage to ensure its visibility and comprehension to those who may not speak English or be familiar with the symbols generally used – Minister for Planning and Infrastructure and local government councils
- Promoting the provision of timely and appropriate water safety programs for all children, including Aboriginal children living in remote areas of the state, children with disability and children from culturally and linguistically diverse backgrounds – Department for Education.

1.9.4. Deaths attributed to suicide

Between 2005 and 2020, 64 deaths have been attributed to suicide. These 64 deaths represent 4% of the total number of child deaths between 2005 and 2020. Forty (62%) of these children and young people were male, and 11 (17%) were Aboriginal children. Fifty-four (84%) of these deaths were of young people aged 15–17 years. Based on the Committee's system of classifying deaths, this data makes suicide the third most common cause of death for young people aged 15–17 years, after transport-related deaths and deaths from natural causes (Figure 20).

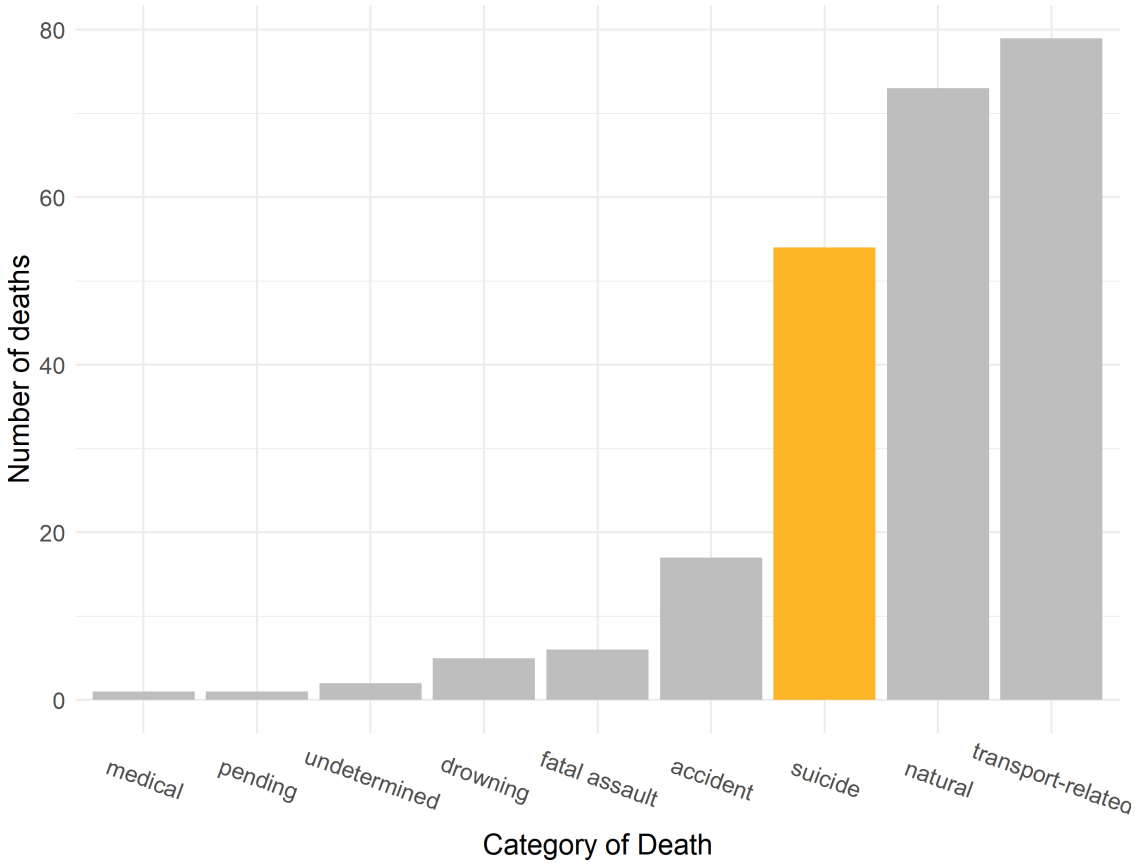

Figure 20: Number of deaths by category of death for young people aged 15–17 years, South Australia 2005–2020

Review of suicide deaths and suicide prevention

The Committee has reviewed 57 suicide deaths using life chart methodology[24]. Based on similarities in their life circumstances, each of the 57 young people who suicided have been placed into one of four groups. Intervention and prevention strategies that are needed to address the issues in each of these groups have been identified.

Group 1

Seventeen young people who suicided have been placed into this group. Fifteen of the 17 were males. These young people faced challenges in their family circumstances, with learning, and with relationships. At the time of their deaths, they were disengaged from family, from learning, and from their peers.

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[24] *Fortune, S. Stewart, A, Yadav, K. and Hawton, K (2007) Suicide in adolescents: using life charts to understand the suicidal process. J Affect Disorders, 100, 199-210.*

Intervention and prevention strategies need to begin early in life for young people to foster positive engagement with home, school, community and other forms of support.

Group 2

Thirty-two of the 57 suicides reviewed were placed into this group. Eighteen of the 32 were male – a much more even split between sexes. The emergence of mental health challenges included depression and anxiety, deliberate self-harm and/or suicide attempts. Seeking help from youth-oriented mental health services was common but engagement was often not maintained.

Youth-oriented mental health services with an emphasis on assertive outreach are needed by young people who experience anxiety, depression and other mental health issues emerging in their teenage years.

Group 3

The life charts of this small group of five young people showed positive engagement with family, their learning and peers. There was little evidence of mental health issues, but they had each experienced difficulties in social, romantic or sexual relationships in the year/months proximal to their suicide.

Readily available support and information services are needed for young people who are facing a 'crisis' in relationships upon which they have placed great emotional value.

Group 4

The Committee does not have enough information about the three young people in Group 4 to determine common themes in their lives. More analysis may be possible in time, should further cases be added to this grouping.

Additional information about each of these groups and proposed prevention strategies can be found in previous annual reports and blog posts[25].

[25] *http://www.cdsirc.sa.gov.au/wp-content/uploads/2019/11/CDSIRC-Annual-Report-2018-19.pdf, Section 1.8.3*
https://cdsirc.sa.gov.au/suicide-prevention-and-child-death-review/

Section Two

2. Committee matters

S30 – Continuation of Child Death and Serious Injury Review Committee

(1) The Child Death and Serious Injury Review Committee established under the *Children's Protection Act 1993* continues in existence.

Children and Young People (Oversight and Advocacy Bodies) Act 2016

2.1. Legislation and purpose

The Child Death and Serious Injury Review Committee operates under Part 4 of the *Children and Young People (Oversight and Advocacy Bodies) Act 2016*.

The role of the Committee is to contribute to the prevention of death or serious injury of children and young people in South Australia.

The Committee reviews the circumstances and causes of death or serious injury to children and young people, and makes recommendations regarding changes to legislation, policies, procedures or practices of government and non-government agencies.

2.2. Committee matters 2020–2021

The Committee met on eleven occasions in 2020–21.

In addition to attendance at these meetings, each member contributed their knowledge and expertise to regular meetings of one or more Special Interest Groups, including child protection, health, disability, suicide prevention, culturally and linguistically diverse families, child safety, and Aboriginal children and young people. In-depth reviews were undertaken by teams drawn from the Committee's membership. The members met as required to plan and complete each review. The average number of out-of-session meetings of Committee members was two per month.

The Committee continued its work in the following areas:

- the timely and accurate collection of information about the circumstances and causes of child deaths
- identifying cases for review, and undertaking reviews of deaths and serious injuries
- making recommendations to the government regarding systemic changes that will contribute to the prevention of similar deaths or serious injuries
- monitoring the progress of the implementation of recommendations
- contributing to government and community knowledge and understanding of the causes of child deaths and serious injuries, and how to prevent them
- maintaining links with interstate and national bodies undertaking similar work.

2.3. Governance and support

The Minister for Education is responsible for the administration of the provisions governing the Committee. Financial and human resource management support is provided by the Department for Education.

The Committee was supported, in this reporting period, by:

Ms Rosemary Byron-Scott	Senior Project Officer (0.6FTE)
Ms Nikki Kearney	Administration and Information Officer (1.0FTE)
Ms Una Sibly	Senior Project Officer (0.4FTE)
Dr Jago Van Dam	Senior Statistician/Data Analyst (1.0FTE)
Dr Sharyn Watts	Executive Officer (1.0FTE)

2.4. The ANZCDR & PG

The Committee continues to support the work of the Australian and New Zealand Child Death Review and Prevention Group.

In May 2021, members of the Secretariat and the Committee attended various sessions held over the course of the virtual, annual two-day meeting. In an update from the Australian Bureau of Statistics (ABS), the contribution of the Committee to the ABS's work in seeking to provide more psycho-social context to its data was acknowledged. Various jurisdictions expressed interest in the work the Committee was undertaking to analyse and review the 'manner' of children's deaths. The Committee will report back on its progress with this analysis at the ANZCDR & PG 2022 meeting. It has also agreed to form part of a sub-committee that will continue to explore the development of a national database of child deaths.

2.5. Future directions

The Committee's Strategic Action Plan 2021–22 has three priorities, with associated objectives:

- Understanding ourselves
    - To be an effective committee with defined roles, responsibilities and expectations of all members

    - Continuous improvement of our knowledge and understanding of issues that impact children, young people and their families
- Building strategic alliances
    - Active engagement with service systems and strategic allies to influence outcomes for children, young people and their families
- Making data real and useful
    - Use our data to build a better understanding of the contribution child death review can make to the safety and wellbeing of children.

Each Special Interest Group sets specific actions that contribute to the achievement of the Committee's priorities.

Section Three

3. Methodology

3.1. Sources of information

3.1.1. Sources of information regarding a death

The *Children and Young People (Oversight and Advocacy Bodies) Act 2016* articulates the role and functions of the Committee and empowers it to obtain information about a case of child death or serious injury from any person (whether or not the person is a state authority, or an officer or employee of a state authority). Using this power, the Committee receives information regarding the death of a child from a range of sources and uses this information in its determinations.

3.1.2. Sources of information regarding birth

The Committee receives the number of live births for each year from Wellbeing SA's Pregnancy Outcome Unit. The live birth count for the reporting year is generally not available at the time the annual report is produced. In such cases, the number of births in the reporting year is predicted based on previous years' data.

As indicated in Section 1.7, the infant death rates for 2020 were calculated using predicted live birth counts (for male, female, and total births). For each group, the number of births in 2020 was predicted by performing a linear regression on the birth counts for the previous five years (2015–2019; all $p < 0.031$; all Adj. $R^2 > 0.775$).

3.1.3. Sources of information regarding population estimates for children and young people in South Australia

The Committee acquires the publicly available number of children and young people resident across the dimensions of calendar year, single year of age, sex, cultural background, and postcode from the Australian Bureau of Statistics. The ABS provides this information in its five-yearly Census of Population and Housing. The estimated resident population is also available on a yearly basis.

For the purposes of this report, the population of children and young people resident in South Australia by calendar year, single year of age, sex, cultural background, and postcode is interpolated as follows: the counts across single year of age, sex, cultural background and postcode are taken from the census, and assigned to the calendar years as three years before each census to two years after the census. The multiplier needed to get from the census to the estimated resident population for each year is found and then applied to each of the 393,984 cells in the matrix calendar year (16

levels), age (18 levels), sex (2 levels), cultural background (2 levels), and postcode (342 levels). The multiplier is found by dividing the estimated resident population by the census count and is performed separately for the Aboriginal and non-Aboriginal populations. Note that when re-aggregated, the adjusted count is the same as the estimate resident population.

3.1.4. Sources of information regarding SEIFA

Socio-Economic Indexes for Areas (SEIFA) is a product developed by the ABS that ranks areas in Australia according to relative socioeconomic advantage and disadvantage. The indexes are based on information from the five-yearly census.

For the purpose of this report, the Committee used the Index of Relative Socio-Economic Disadvantage (IRSD). The postcode of the usual residence of each child or young person who died was matched to the appropriate SEIFA/IRSD level extracted from the census nearest their year of death. Deciles were collapsed into quintiles: on this scale, quintile 1 includes areas with the greatest relative socioeconomic disadvantage and quintile 5 includes areas with the least relative socioeconomic disadvantage.

3.2. Committee classifications and definitions

3.2.1. Operational definition of death

The Committee receives information regarding the death of a child or young person in South Australia from three government sources: Births, Deaths and Marriages; the Coroner's Court of South Australia; and the Pregnancy Outcome Unit. The count of deaths in this annual report includes all cases received from these sources with the following exceptions:

- if the Committee understands from the information gathered that the case was a termination of pregnancy
- if the Committee understands that the death occurred after the birth of an infant, prior to 20 weeks gestation.

Where there is disagreement between the sources, the Committee reviews all of the available evidence to arrive at a conclusion.

3.2.2. Cultural background

To differentiate grouping, the ABS uses the categories of 'Aboriginal', 'Torres Strait Islander', 'Both Aboriginal and Torres Strait Islander', 'Not stated' and 'Non-Indigenous'. For the purpose of this report, the Committee collapses these categories into two groups: 'Aboriginal' = 'Aboriginal', 'Torres Strait Islander', 'Both Aboriginal and Torres Strait Islander'; and 'Other' = 'Not stated' and 'Non-Indigenous'.

It is important to note that the Committee's determination of the cultural background of a deceased child or young person uses multiple administrative sources[26].

3.2.3. Category of death

In many cases, the Committee has multiple sources of information available about children and young people and is not limited to the causes of death recorded in post-mortem reports or death certificates. At the time of classifying a death, the Committee will consider all available information.

Table 2: Committee's cause of death classification

Cause	Committee classification
Transport–related	Transport-related deaths include deaths resulting from incidents involving a device used for, or designed to be used for, moving people or goods from one place to another. These incidents may involve pedestrians and include railway or water transport.
Accidents	Accidents exclude deaths attributed to transport incidents, fires or drowning. Also referred to as deaths from unintentional injuries, these deaths most commonly include accidental: suffocation, strangulation and choking, falls, and poisoning.
Suicide	The Committee's definition of suicide is: *Taking one's own life, intending to do so.* The Committee defines a death as suicide if, after a thorough review of all available evidence, it is satisfied that the young person killed him or herself, intending to take their own life. Since adopting this definition, three cases previously attributed to suicide have been reclassified as accidental deaths, resulting from misadventure.
A deliberate act by another causing death	Describes a range of deaths, including deaths from acts of violence, where a person, by whatever means, causes a child's death by a deliberate act. While a person's intent is obviously relevant to issues of criminal liability, for the Committee's categorisation of deaths, this does not need to be considered. Similarly, there may be cases where the person who causes a child's death does so as a result of mental illness, leading to a Court finding of mental incompetence. Such cases are also included in this category. It will not always be possible, based on the available evidence, to be certain that a child's death resulted from a deliberate act by another person. For instance, a child may have serious head

[26] *Gialamas A, Pilkington R, Berry J, Scalzi D, Gibson O, Brown A, Lynch J. Identification of Aboriginal children using linked administrative data: Consequences for measuring inequalities Journal of Paediatrics and Child Health 52 (5), 534-540.*

	injuries causing death, where it is not possible to say that the injuries were deliberately inflicted, as opposed to being caused by an accidental fall. In such cases, upon consideration of all the available evidence, the Committee will decide which is the most likely cause of death.
Neglect	The Committee defines neglect as 'a death resulting from an act of omission by the child's carer(s)' including: • failure to provide for the child's basic needs • abandonment • inadequate supervision, and • refusal or delay in provision of medical care. This definition can account for both chronic neglect and single incidents of neglect, or a combination of both[27].
Health-system related	These deaths have been classified as such by the Committee based on written records which may not necessarily be complete. The Committee places a death in this category based on consideration of preventable aspects in the circumstances of the death, and a focus on future prevention strategies rather than an investigation of the cause of death.
Sudden unexpected infant death	Sudden Unexpected Death in Infancy (SUDI) has been described as an 'umbrella' term that is used for all sudden unexpected deaths of infants. The definition of SUDI is based on the definition, proposed by Fleming et al. (2000)[28], and includes infants from birth to 365 completed days of life whose deaths: Criterion 1: Were unexpected and unexplained at autopsy; Criterion 2: Occurred in the course of an acute illness that was not recognised by carers and/or by health professionals as potentially life-threatening; Criterion 3: Arose from a pre-existing condition that had not been previously recognised by health professionals; or Criterion 4: Resulted from any form of accident, trauma, or poisoning.
Sudden infant death syndrome	Sudden Infant Death Syndrome (SIDS) is a term used to describe the sudden and unexpected death of an infant, when the death occurs during sleep, and when the cause of death remains unexplained after a complete autopsy, review of the circumstances of death, and of the infant's clinical history[29].

3.2.4. Disability

The definition used to determine inclusion as the death of a child or young person aged 1 to 17 years with disability is:

- the child or young person was over one year of age at the time of death
- the child or young person's daily activities were limited due to their disability, illness, disease or health problem; and
- the child or young person's daily activities were adversely affected for a period of six months or more.

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[27] *Lawrence R, & Irvine P.* Redefining fatal child neglect. Child Abuse and Prevention, 21, *1-22.*
[28] *Fleming P, Bacon C, Blair B, and Berry PJ. (2000)* Sudden unexpected deaths in infancy, the CESDI studies 1993-1996. *London: The Stationery Office.*
[29] *Krous H, Beckwith J, Byard R, Rognum T, Bajanowsky T, Corey T, Gutz E, Hanzlik R, Keens T, and Mitchell E. (2004) Sudden infant death syndrome and Unclassified infant deaths: A definitional and diagnostic approach.* Paediatrics, 114*, 234–238.*

Where the length of time during which the child or young person's daily activities were adversely affected was unknown, the case was not included on the register. Cases where the child or young person had a chronic health condition (eg, asthma, epilepsy, diabetes) were only included on the register if other disabilities were present. Some children and young people have multiple types of disability, for example cerebral palsy and epilepsy. Multiple disabilities are recorded for each child or young person, where identified.

Table 3: Committee's definition of disabilities

Disability	Committee definition
Neurodegenerative diseases, genetic disorders and birth defects	This category included all instances of neurodegenerative diseases, genetic disorders and birth defects, including in-born errors of metabolism where the child's health deteriorates over time. Children with many of these conditions are likely to die as a result of their disease, and they require significant care as their condition progresses.
Cerebral palsy	This category includes all cases of cerebral palsy, which is a term used to describe a group of non-progressive motor function disorders that arise because of damage to, or dysfunction of, the developing brain. This permanent condition can affect body movement, muscle control, muscle coordination, muscle tone, reflex, posture and balance. It may also cause visual, learning, hearing, speech and intellectual impairments, as well as epilepsy.
Epilepsy	Using the guidelines developed to identify disability, this category only included cases where the frequency and severity of the child's epilepsy adversely affected their daily activities for a period of six months or more, or the child with epilepsy had associated disability. Epilepsy is a common disorder that is characterised by recurring seizures or sudden, uncontrolled surges in the normal electrical activity in all, or part of, the brain. While the Epilepsy Centre notes that epilepsy can mostly be controlled by taking medication and restricting daily living activities, epilepsy can be associated with sudden unexpected death.
Heart and circulatory problems	This category included all cases where a condition involving the heart or blood vessels was able to be identified, regardless of whether the condition resulted from an infection or from a birth defect. Children with conditions such as complex congenital heart defects or myocardiopathy are, without life-saving surgery such as a heart transplant, at higher risk of dying as a result of their heart or circulatory problems.
Intellectual disability	This category included all cases where the available information suggested that the child had some form of intellectual disability. It was identified as a specific category because it is a developmental disorder, and people living with such disorders have significantly more difficulty than others in integrating new learning, understanding concepts and solving problems.
Autism spectrum disorder	Autism Spectrum Disorder is a lifelong developmental disability that affects, among other things, the way a child relates to his or her environment, and their interactions with other people. Where information was available indicating a diagnosis of ASD had been made, the child was placed in this category.
Other types of disability	This category accommodated all of the remaining disability types in children on the Disability Register. It incorporated cases where a child had conditions such as Epstein-Barr virus, systemic lupus, and community acquired pneumonia. It also included cases where the available information was too limited to confidently assign the case to a specified category.
Cancer and 'disabling medical conditions'	The Disability team considered that the issues arising from these deaths were primarily about the medical management of these conditions rather than about issues arising from the disability caused by their impact on the child. These deaths will be reported as deaths from illness or disease.

Infants with disability

There is a unique set of challenges associated with identifying disability in infants. A set of criteria has been developed by the Committee to identify the deaths of infants with a disability. Deaths are excluded from consideration if the underlying cause is: prematurity alone; prematurity and maternal factors; infection; haemorrhage; digestive or respiratory problems; cancer; heart disease, including myocarditis and cardiomyopathy; or, congenital malformations of major organs such as heart, kidney and liver.

Once these cases are excluded, the remaining deaths are then reviewed by the Disability Special Interest Group, and a decision made about inclusion in the Disability Register based on the available information. Multiple types of disability are not recorded for infants under one year of age.

3.2.5. Contact with the child protection system

To be included in this section of the report, the child, young person, or a member of their family must have had some form of contact with DCP or its predecessors within three years of the incident resulting in their death. The guardianship status of a child, young person, or their parent(s) is determined during this process, whether in South Australia or in another Australian state or territory.

3.3. Coding death using ICD-10

All deaths registered by the Committee are coded according to the International Classification of Diseases, Version 10 (2016) developed by the World Health Organization. This system is accepted as the world standard diagnostic classification system for all general mortality and morbidity classifications[30].

3.3.1. Code blocks and the analysis of neonatal deaths

ICD-10 codes are arranged into chapters and blocks (groups of related codes within a chapter). Neonatal deaths are almost always assigned codes belonging to chapters 16 or 17. Chapter 16 describes 'Certain conditions originating in the perinatal period'[31], while Chapter 17 describes 'Congenital malformations, deformations and chromosomal

[30] *https://www.who.int/classifications/icd/icdonlineversions/en/*
[31] *https://icd.who.int/browse10/2019/en#/XVI*

abnormalities'[32]. It is important to note that deaths are not uniformly distributed amongst the many codes in these chapters: most deaths are assigned one of a relatively small subset of codes describing the most common disorders. Nevertheless, many specific codes are present in the data presented in Section 1.7.1. Thus, to perform quantitative analyses, it was necessary to aggregate the data into a structure broader than individual codes but narrower than chapters.

Code blocks serve just this purpose, and are also useful in interpreting the data, as they describe distinct types of conditions and causes of death, including 'Fetus and newborn affected by maternal factors and by complications of pregnancy, labour and delivery' (block P00-P04) and 'Disorders related to length of gestation and fetal growth' (block P05-P08). Within block P00-P04, most deaths are attributed to just a handful of codes, with the most common being P02.7 (Fetus and newborn affected by chorioamnionitis) and P02.1 (Fetus and newborn affected by other forms of placental separation and haemorrhage). In block P05-P08, the majority of deaths are assigned codes P07.0 (Extremely low birth weight) or P07.2 (Extreme immaturity).

The blocks presented in Figure 12 are those with an average yearly count of at least 1. Thus, while other blocks are present in the data, they occur very rarely and had expected counts of less than 1 in 2019.

3.4. In-depth review process

Deaths screened by the Committee are assigned one of the following criteria:

- Eligible for review – a case will only be considered eligible for review under Section 37(2) of the Act, if the incident resulting in the death or serious injury occurred in the state; or the child or young person was, at the time of their death or serious injury, ordinarily resident in the state.
- Not for review – a case may not require in-depth review if the screening of information available at the time indicated that there are no systemic issues arising from the death. These cases are assigned a category of death, eg, illness or disease, SUDI, transport, deliberate acts etc, and the details are kept on the Committee's database. They are included in the relevant annual report. They may be included in reviews in later years, where features from cases

[32] *https://icd.who.int/browse10/2019/en#/XVII*

aggregated over a number of years suggest that there may be systemic issues that can be addressed.

- Pending further information – in some cases the Committee requests further information before making a decision regarding in-depth review.
- Pending completion of investigations – in accordance with Section 37(4) of the Act, the Committee must not undertake a review if there is a risk that the review would compromise an ongoing criminal investigation and must wait until coronial investigations are complete.
- Awaiting assignment – in any reporting year, there are also cases ready for review but awaiting assignment to a 'review team'. The number of cases pending investigation or review gradually decreases during any year as information is obtained, cases are finalised in the criminal and coronial systems, and the Committee makes a determination about further review.

3.5. Reporting requirements

Section 39 of the Act outlines the reporting responsibilities of the Committee. It requires the Committee to report periodically to the Minister for Education, and also to provide an annual report on the performance of its statutory functions for the preceding financial year. The Committee submits a report to the Minister for Education at the conclusion of each in-depth review. The report contains the Committee's recommendations about systemic or legislative issues that may contribute to the prevention of similar deaths or serious injuries.